EXAMINING THE PSYCHOLOGICAL AND EMOTIONAL EXPERIENCE OF SEXUALITY FOR MEN AFTER SPINAL CORD INJURY

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ABSTRACT

Background: Spinal cord injury (SCI) affects motor and sensory function, psychosocial well-being and affects multiple body systems including those involved in sexual function (Biering-Sørensen, Bolling-Hansen & Biering-Sørensen, 2012). Sexuality is a basic human necessity and is a vital component for achieving satisfaction with one's overall quality of life (QOL) (Reitz, Tobe, Knapp, & Schurch, 2004). Literature regarding sexuality for men after SCI has focused primarily on physical components, however, sexuality is multifaceted and the psychosocial aspects may be more important than the physical factors for achieving satisfaction with sexual life in this population (Kreuter, Siösteen & Biering-Sørensen, 2008). **Objectives:** 1) Examine issues of sexuality for men after SCI with a focus on the psychological and emotional aspects, and 2) determine whether healthcare provider perspectives of sexuality for men after SCI align with lived experiences and priorites of their patients. **Methods/Participants:** Study I, Papers 1 and 2: In-depth phenomenological interviews with six men living with SCI. Study II, Paper 3: Delphi method involving an expert panel of 20 men with SCI. Study III, Paper 4: Delphi method involving an expert panel of 13 healthcare providers who work with men who have a SCI. **Results:** Men with SCI described an evolved meaning of sexuality, placing more emphasis on psychological and emotional aspects such as connection and intimacy. A lack of relevant resources and sexual education was reported by men with SCI, and healthcare providers lacked confidence in their ability to address issues of sexuality. **Conclusions/Future Directions:** To support sexuality for men after SCI, healthcare providers must first understand the experience of sexuality from the patient perspective including the shift from a physical, genital focus to a deeper, more emotive meaning of sexuality. Areas where healthcare provider perspectives are misaligned with patient experiences should be addressed. Future sexual education and sexual rehabilitation initiatives should be co-created with input from the patient, healthcare provider, researcher and previous literature to improve overall life satisfaction for men after SCI.

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SCI- Spinal cord injury
QOL- Quality of life
AD- Autonomic dysreflexia

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STATEMENT OF WORK

This PhD dissertation reflects the work of the candidate with minimal contribution, suggestion and editing from the supervisor and the committee.

CHAPTER 1: INTRODUCTION AND LITERATURE REVIEW

Introduction

"It's [sex] way different because I focused solely on genitalia [prior to SCI]. …it took a while at the beginning because you think of sex from a physical standpoint. You don't think of it from an emotional standpoint. ...It [SCI] just opened my mind to a whole different level of sexuality because guys are normally not taught to be emotional in any way. It's just the whole physical aspect of it. ...there could have been a hole in a wall, and I would be like 'oh yeah I can masturbate with that.' You're not taught to be emotional or in contact with your own sexuality in that way. ...It's much more fulfilling in my opinion to be connected with your partner emotionally than it is just the physical aspect. ...I honestly don't think [I would have gotten to this level of sexual fulfilment] because I would have been concentrating so much on the actual release of an orgasm, like the physical aspect of it… I don't know if that would have gotten in the way of understanding that level of intimacy. The actual physical aspect of feeling your genitalia and you know, wanting to have that physical release… is actually in the way of your emotions. …You really have to look at it from a different perspective. And you can't look at it from your typical male perspective. …it's not just about getting off. It's about being connected. And it [SCI] really taught me that. That physical release, you have to find it from a different avenue of connection. And it's more fulfilling being this way than it is being the other way."- Steve

i. Spinal Cord Injury

Interviewer: *"Right, okay, and can you comment on how your spinal cord injury has impacted your life in a general sense?"*
Elliott: *(laughs) "That's definitely a huge question. So, I mean, it impacted every part of my life in every single way. So, whether it's my ability to jump out of bed and jump into the shower and get out of the shower and get dressed in 15 minutes if I have to. That's definitely never gonna happen again. Because every day I have a bowel routine, a shower, and I have people helping me so that 15-20 minutes is now a minimum of 2 hours every morning. And on top of that, any sort of spontaneity, is virtually none of that. Everything has to be planned very down to the "T." I need to know what's happening every hour of the day basically in order to have life run kind of smoothly. Whether it's umm... trips to a bathroom, or... umm... anything from meals... to sort of who's helping me get into bed tomorrow night or tonight. So yeah, there's definitely a lot planning that goes on in my life. Lots and lots of planning."*

Interviewer: *"How do you feel the injury has impacted your life in general?"*
Joe: *"So massively. Obviously, it's a life-changing injury, but uhh... I think the biggest part for me is the psychological effect of it. You have to restart and rebuild everything, and the first 6 months, it's a pretty hard time. You can't see any way forward…"*
Interviewer: "You said that the psychological part was the hardest part to deal with after the injury. Did you find the psychological aspects were even more difficult in the beginning than managing the changes in your physical abilities?"
Joe: "Yeah, you're lying in bed and all you can do is think about the future or lack thereof that's in your mind, and you're suffocating to get up and go for a walk to blow off some steam or something. It's definitely tricky."

Spinal cord injury (SCI) is a potentially devastating condition with a profound impact on every aspect of that individual's life. After injury, up to two years may be spent in acute and inpatient rehabilitation facilities and outpatient rehabilitation services, followed by a lifelong struggle to maintain health and well-being while managing numerous secondary health conditions (Craven et al., 2014). Multiple body systems may be affected resulting in significant changes to body functions and mobility. These changes may have a tremendous effect on one's overall day-to-day life as explained by the participants in this research and outlined in the excerpts from the interview transcripts presented above.

A spinal cord injury (SCI) will cause disruption of descending spinal voluntary motor pathways and involuntary autonomic pathways resulting in a number of body dysfunctions (Krassioukov et al., 2012). Approximately 86,000 people across Canada are affected by SCI (Rick Hansen Institute, 2020), and it is estimated that in Ontario, 11 people will sustain a new SCI each week (sciontario.org). Men represent a larger portion of this population, and data for the province suggest that 68.4% of those living with SCI are male, though it has been consistently reported across the literature that men typically account for approximately 80% of this population (National Spinal Cord Injury Statistical Center, 2016; Rick Hansen Institute, 2020). Young adults between the ages of 20-29 are most likely to sustain a SCI (sciontario.org). Statistics would therefore suggest that SCI most commonly occurs in young men at a point in their lives during which fertility and sexual activity levels are at their peak (Courtois et al., 2012; Ibrahim, Lynne & Brackett, 2016; Reitz et al., 2004; Sinha, Elliott, Ibrahim, Lynne & Brakett, 2017). A SCI will affect motor, sensory and psychological functioning, and will affect multiple body systems, including those involved in sexual function (Biering-Sørensen et al., 2012).

ii. Sexuality

"Sexuality, in my head, is an essential part of being a human many ways." - Peter

Sexuality is a complex phenomenon that is comprised of physical, psychological and social inputs. Sexuality is an evolving construct that is experienced by each person in a unique way (Consortium for Spinal Cord Medicine, 2010) and is a part of one's personal identity (Northcott & Chard, 2018). It embodies cultural and moral beliefs, and is informed by how one relates to themself, and to society (Consortium for Spinal Cord Medicine, 2010). Sexuality is a basic human necessity (Pieters, Kedde & Bender, 2018) and part of the human experience that is critical for achieving satisfaction with one's overall quality of life (QOL) (Reitz et al., 2004), fulfillment and feelings of connection with oneself and with others (Consortium for Spinal Cord Medicine, 2010). The World Health Organization acknowledges sexual health as a right of all people, stating "Sexual health is fundamental to the physical and emotional health and well-being of individuals, couples and families, and ultimately to the social and economic development of communities and countries (WHO, 2015, p.4)." The American Occupational Therapy Association recognizes sexuality as an activity of daily living (AOTA, 2014) which are "fundamental to living in a social world; they enable basic survival and well-being (Christiansen & Hammecker, 2001, p.156)."

Sexuality is dependent on shared social meanings and expectations that are embedded in the environment (Simon & Gagnon, 1986). A script guides and makes sense of behaviours, and is the basis for behaviour within society. Any behaviour that is not biologically programmed is therefore a script (Simon & Gagnon, 1986). Sexual scripts are the blueprints for one's sexual behaviours (Jones & Hostler, 2002). They are comprised of accepted social and cultural norms that are internalized and validated through socialization (Simon & Gagnon, 1986) and unconsciously guide one's sexual actions (Frey & Hojjat, 1998). Sexual scripts are obtained during childhood and are used throughout life to interpret and respond to sexual encounters (Simon & Gagnon, 1986). Sexual scripts are shaped by individual and subjective understandings of sexuality that inform one's sexual actions and the subsequent emotional responses to, and experience and meaning of those sexual actions (Gagnon, Rosen & Leiblum, 1982; Jones & Hostler, 2001).

iii. Sexuality and Disability

"I recognize and acknowledge the fact that when you're meeting new people for the first time, the [wheel] chair is the first thing that many of them will see. Some people can't get past it. It's [SCI] always there in one way or another… people wondering how they can help me, if I need help…" - Will

Due to socially constructed ideals, sexuality and disability has been deemed a taboo subject (Northcott & Chard, 2000; Sharma, Singh, Dorga & Gupta, 2006; Esmail, Darry, Walter & Knupp, 2010) that has been disregarded and stigmatized (Neufeld, Klingbeil, Bryen, Silverman & Thomas, 2002). The thought of sex and disability may be uncomfortable on a moral and/or ethical level (Dyar & das Nair, 2012), and though attitudes are evolving with regards to sexual norms (Hohmann, 1972), this may not extend to individuals living with a disability who continue to be desexualized (Tepper, 2000).

Participation in sexual activity is typically reserved for individuals who do not have a disability (Tepper, 2000). Individuals with a disability are omitted from representations of sexuality, are not considered viable sexual partners and experience reduced sexual opportunities (Overstreet, 2008). Myths and stereotypes continue to exist in society about the sexuality of individuals living with a disability and include the notion that they are asexual (Esmail et al., 2010) due to an inability to participate in sexual activities or a lack of interest in doing so (Tremain, 1996; Tepper, 1999; Milligan & Neufeldt, 2001; Thompson, Bryson & De Castell, 2001; Elliott et al., 2019). According to the medical model of disability, a disability is the inability to conform to what is "normal" (Nagi, 1964), and these individuals must be seen as asexual because they cannot participate in in sexual activities in a way that is viewed as "normal" (Federici et al., 2019). A shift has been initiated towards the social model of disability which views disability as a social construct (Esmail et al., 2010) resulting from social and environmental barriers (Galvin, 2005). To support this model, attitudes must be adjusted to believe that issues lie within society, and do not belong to the individual living with a disability. Additionally, barriers of sexuality and disability must be identified and removed from society (Esmail et al., 2010).

Individuals who live with a disability internalize harmful societal beliefs (Esmail et al., 2010) and these beliefs may have a more profound negative effect on one's sexuality than the disability itself (Neufeld et al., 2002; Mayers, Heller & Heller, 2003). Problems with sexual health are more prevalent among those with disabilities, and these issues often affect sexual satisfaction, sexual-esteem and body-esteem (Fisher et al., 2002; Pieters et al., 2018). *Body-esteem* is the overall evaluation of one's body in either a positive or negative way. *Sexual-esteem* describes one's confidence in his/her ability to experience sexuality in a satisfying way. Having a physical disability has the potential to adversely affect both of these paradigms (New, 2019). Sexual satisfaction and body-esteem are important contributors to the general well-being of individuals with a disability (Shakepeare, Gillespie-Sells & Davies, 1996; Shuttleworth, 2000; Taleporos & McCabe, 2001; Taleporos, 2002). Taleporos and colleagues (2002) investigated the relationship between sexuality and psychological well-being in those with disabilities compared to able-bodied individuals and found sexual-esteem to be closely linked with self-esteem in men, and found sexual well-being and body-esteem were more closely associated with overall psychological well-being in those with disabilities than their able-bodied counterparts.

Participating in behaviors that increase self-esteem, including sexual relationships, has been shown to reduce medical complaints and decrease the need for medical and/or social support in individuals living with a disability or chronic disease (Anderson & Cole, 1975). Furthermore, improvements to one's sense of sexual-self will enhance overall QOL after SCI (Anderson, Borisoff, Johnson, Steins & Elliott, 2007; Anderson, Borisoff, Johnson, Steins & Elliott, 2007).

iii. Sexuality and Spinal Cord Injury

"I was deeply concerned about my sexual capabilities from the moment the breathing apparatus was removed and I was able to speak again." - Mitchell Tepper

"Any time I think about engaging in any type of sexual activity, that's the next thing I think about… all of the other crap I'm going to have to deal with. Whether it's pain or anything else. And it makes me a little

more anxious, because at the same time, I am also questioning my so-called performance… am I going to be able to satisfy my partner if I'm dealing with all of these other things. And am I letting my partner down because I'm not interested in [having sex] and dealing with these things all the time?" - Paul

A spinal cord injury will affect numerous aspects of an individual's life including sexuality and sexual functioning (Courtois et al., 2012). The extent to which SCI affects sexuality will depend on the level and completeness of the injury (Ricciardi, Szabo & Yibarren Poullos, 2007; Consortium for Spinal Cord Medicine, 2010).

Sexuality is a fundamental component of the human experience, and therefore perseveres in both health and disability (Davidson, Elliott & Krassioukov, 2016; Kreuter, Sullivan & Siösteen, 1994). Sexual function has been identified as a top therapeutic priority for individuals with SCI (Anderson, 2004) and is an important factor in the overall rehabilitation of this population (Sheel, Krassioukov, Inglis & Elliott, 2005). Sexuality was one of the most frequently identified and enduring concerns of patients with SCI at one- and five-years post-discharge from rehabilitation (Van der Meer et al., 2017). In a study by Simpson and colleagues (2012), restoration of sexual function was consistently reported as a top priority (within the top 25%) for individuals with SCI. A study by Anderson and colleagues (2004) found sexual function to be the number one therapeutic priority for paraplegics and the second most important therapeutic priority for tetraplegics. In this study, sexual function was ranked even higher in importance than regaining the ability to walk. Furthermore, Kennedy and colleagues (2006) surveyed 350 individuals living with SCI who identified sexual activity as the greatest unmet need for this population.

Individuals with SCI remain sexual beings post-injury and may continue to lead fulfilling sexual lives (Reitz et al., 2004), however, individuals living with a disability or chronic illness such as SCI are more likely to experience physical and emotional issues with sexual health than the general population (Pieters et al., 2018). Gianotten and colleagues (2006) estimated the percentage of adults living with various disabilities who experienced sexual difficulties and estimated that 100% of individuals with SCI

experience challenges with their sexuality. This was the highest rating among the nine patient groups that were considered. In a pilot study by Elliot and colleagues (2019), a majority of participants with SCI reported being unsatisfied with their sexual lives and felt strongly that their injury interfered with sexual interest, sexual activity and sexual self-esteem.

In society, sexuality is often confused with sexual intercourse, however, sexuality is a complex phenomenon that is comprised of physiological, as well as psychological, social and emotional domains (Northcott & Chard, 2000). Sexual desire is a psychological component of sexuality rather than a physical component (Cardoso, Savall & Mendes, 2009). As a result, sexual desire may be unaltered after SCI despite decreases in mobility and sensation (Sakellariou & Sawada, 2006; Siösteen et al., 1990) as desire is not directly affected by the injury (Cardoso et al., 2009). Additionally, sexual adjustment is not solely dependent on residual genital function or level of injury (Siösteen, Lundqvist, Blomstrand, Sullivan & Sullivan, 1990). Kreuter and colleagues (1996) suggest that sexuality is not synonymous with genital function, and that the emotional and sensual dimensions of sexuality may compensate for physical limitations resulting from SCI. The mind itself can create sensual experiences independent of the genitals (Money, 1960). Orgasm has been defined as a "subjective experience of sexual climax with or without ejaculation" (Dahlberg Alaranta, Kautiainen & Kotila, 2007), and because orgasm is a psychological phenomenon, it is possible to experience orgasm without intact genital functioning (Stein, 1992). Spinal cord injury does not eliminate sexual feelings or the need for physical and emotional sexual intimacy. In a study of 86 men with SCI, 93% continued to be interested in sex post-injury (Sharma, et al., 2006). In a study of Greek men with SCI, sexuality was an important concern early after injury and none of the participants experienced reductions in sexual desire over time (Sakellariou & Sawada, 2006) and Cardoso and colleagues (2009) found no significant difference in the level of sexual desire between 40 men with SCI and a control group.

Despite the continued importance of sexuality, sexual education is often poorly integrated into healthcare

models (McLaughlin & Cregan, 2005) and is rarely included in the training curriculum of healthcare providers (Gianotten et al., 2006). As a result, the topic of sexuality is often neglected by healthcare provides (Craven et al., 2012; Elliot et al., 2019), and patients receive insufficient assistance regarding their sexual concerns (Stein, Sauder & Reale, 2018). In a study of 20 individuals with SCI, participants expressed that their healthcare providers had not provided them with information regarding their sexual health post-injury (Elliott et al., 2019). In a study of 12 individuals living with SCI, most reported being dissatisfied with the quality and quantity of sexual health supports they received (McAlonan, 1995), and all of the men in a phenomenological study by Basson and colleagues (2003) reported a lack of sexual education during rehabilitation which led to uncertainty, apprehension and frustration regarding their sexuality. While the demand for sexual education and counselling post-SCI have generally been inadequately met, Morgan and colleagues (1971) found that when sexual counselling had been provided, patients reported it to be the service of greatest benefit. Conversely, patients have reported feelings of frustration, embarrassment, intimidation and disappointment when their healthcare providers have been reluctant to, or incapable of, addressing sexuality (McAlonan, 1995).

iv. Sexuality for Men with Spinal Cord Injury

"What happens when we do not have our penis to fall back on or to stand up and let us be counted as a man?" - Mitchell Tepper

"Manhood is conditional rather than absolute…But if a man isn't a man, what then is he? The answer most seem to believe is: Nothing at all." - Zilbergeld

A continuously expanding body of literature exists supporting the importance of discussing sexual health for men after SCI. Nevertheless, the topics of sex and sexuality continue to be under addressed (Aikman, Oliffe, Kelly & McCuaig, 2018). In terms of sexuality for men after SCI, the literature has focused primarily on physical aspects such as obtaining and maintaining an erection, and successful ejaculation (Anderson et al., 2007; Ide & Ogata, 1995; Verschuren, Enzlin, Dijkstra, Geertzen & Deker, 2010;

Willmuth, 1987). Emphasis has been placed on sexual performance (Sunilkumar, Boston & Rajagopal, 2015) and fertility (Willmuth, 1987; Craven, 2012). While sexuality and fertility are related, they are not the same, and addressing one's fertility does not mean that his or her sexuality has been considered. Participation in sexual activity is important to individuals with SCI for a number of reasons including maintaining closeness and intimacy in a relationship (Cramp, Courtois, Connolly, Cosby & Ditor, 2014), and the majority of participation in sexual activity is for the purpose of sexual enjoyment, not procreation (Talbot, 1971). In previous research involving 286 individuals living with SCI, more than half reported the primary purpose for participating in sexual activities was to experience intimacy (57.7%) and only 1% conveyed that their participation in sexual activity was for fertility (Anderson et al., 2007).

Broader meanings of sexuality including the psychological and emotional aspects have been largely neglected for men with SCI (Basson et al., 2003). However, sexuality is multifaceted and the psychosocial aspects may be more important than the physical factors for achieving satisfaction with sexual life in this population (Kretuer et al., 1994; Siösteen et al., 1990). Previous literature has demonstrated that the meaning of sexuality changed, expanded and became more holistic for women post-SCI. While sexuality continued to include a physical component for these women, participants experienced a shift from genital focus to whole body focus, less emphasis on physical sexual aspects, increased intimacy, and a shift from experiencing sexuality as a bodily phenomenon to a mental phenomenon (Leibowitz & Stanton, 2007). It is imperative that research considers the psychological and emotional components of sexuality for men after SCI to gain a better understanding of this relationship and its effect on satisfaction with sexual life and overall QOL post-injury.

Problems with arousal, erection, orgasm and fertility are common for men after SCI (Alexander, Sipski & Findley, 1993; Hammond & Burns, 2009; Schopp, Good, Mazurek, Berker & Stucky, 2007; White, Rintala, Hart, Young & Fuhrer, 1992) and may negatively affect sexuality, self-identity and manhood (Sakellariou, 2006). Socially prescribed constructs related to masculinity and male sexuality contribute to

internalized beliefs about what it means to be a man (Tepper, 1999). According to Tepper (1999), "the end result of male socialization is a set of defaults that are programmed by society, culture, media, family and religion," and a man with SCI may not embody the traits and characteristics used by society to define a man. Masculinity has been linked to a man's penis and his ability to have and use erections. When the sexual organ does not function the way a man has been taught to believe it should, he may experience feelings of loss regarding his manhood (Zilbergeld, 1992). Changes to sexual function as a result of SCI have been correlated with shifts on the masculinity-femininity scale. Using the Gender Role Definition Scale of the Derogatis Sexual Functioning Inventory (DSFI), Romeo and colleagues (1993) found that men with SCI tended to identify with more traditionally feminine characteristics as a result of the injury. In an internet-based survey of 116 men with SCI, Burns and colleagues (2010) found that men with SCI who strongly adhered to masculine norms emphasizing men's sexual prowess had higher rates of depression, insecurity, inadequacy and loss which may restrict positive sexual adjustment after SCI. In this study, men adhering to masculine norms were not as open to accessing emotional and/or physical supports as men who did not adhere to these norms as strongly.

Sexual scripts define what actions are acceptable and appropriate for expressing oneself sexually based on that person's status and role (Reed & Weinberg, 1984). Cultural scenarios provide the socially constructed requirements for specific roles, however these may be too generic to fit all circumstances (Simon & Gagnon, 1986). Sexual scripts for men convey that men should always be willing and ready to participate in sexual activities, and that they should be sexually dominant (Courtenay, 2000; Stephens & Eaton, 2014). Male sexual scripts focus on the penis, erection, penetration, sexual stamina and sexual performance (Rutagumirwa & Bailey, 2018), but this scrip may not adequately describe the role of a man living with SCI. Rutagumirwa and Bailey (2018) found that adherence to masculine sexual scripts negatively affected the sexuality of older men, created negative emotional responses such as anxiety, fear and distress, and was harmful to their self-esteem and well-being. Their inability to meet expectations of social scripts impaired their sense of masculinity. Furthermore, social scripts embraced silencing norms

for men, teaching them to hide their sexual issues and to avoid asking healthcare providers for support or treatment for such problems.

A lack of qualitative research exists regarding body-image and self-concept for men with SCI (Sheldon, Renwich & Yoshida, 2011). A number of investigations have made an effort to explore the relationship between self-esteem and sexual-esteem (Taleporos, Dip & McCabe, 2002; Tepper, Whipple, Richards & Komisaruk, 2001), body-esteem (Kreuter et al., 2008; Reitz et al., 2004; White et al., 1993) and emotional closeness in a relationship (Fritz, Dillaway & Lysack, 2015) for women after SCI, and it is necessary that similar research be conducted for men with SCI (Sheldon et al., 2011).

Materials and Methods

Qualitative Research, Phenomenology and World View

Qualitative research methods are inductive and exploratory in nature. They are well suited to topics that are novel, sensitive, exploratory and complex (Creswell, 2007), such as sexuality and disability. In-depth interviews generate rich and detailed data while allowing the researcher to collect information that pertain to a phenomenon that cannot be observed (Patton, 2002). In-depth interviews permit the informant to share his or her experiences in their own words, and allow the researcher to enter the informant's lived world (Kvale, 2007). In-depth interviews are the primary method of data collection when using phenomenology (Patton, 2002).

The goal of phenomenology is to uncover the lived experiences and the meanings attached to those experiences for a person, or people, who have first-hand knowledge of that particular phenomenon (Creswell, 2007). It acknowledges that no two people will have the same experience (van Manen, 2001), but that patterns emerging from informants' unique experiences are valuable as they capture the core

understandings of a phenomenon across contexts to identify factors of particular interest (Qualitative Research & Evaluative Methods, 3rd ed, 2002, pg. 235, 243).

Phenomenology can be either descriptive (eidetic) or interpretive (hermeneutic) (Cohen & Omery, 1994). The objective of descriptive phenomenology is to adequately describe a phenomenon with little interpretation, whereas interpretive phenomenology allows the researcher to call upon his or her own personal experience with the phenomenon to interpret the meaning behind it. As the researcher of the present investigation is an able-bodied female with no first-hand knowledge of the phenomenon, it is appropriate that a descriptive phenomenological approach be applied to the qualitative component of this research to describe the experiences of sexuality for men after SCI.

A researcher's attitudes and worldview will, in some way, influence the research they conduct. Qualitative research requires the researcher to be transparent in his or her beliefs and biases as they will impact the methods employed, and will influence the interpretation and presentation of findings (Creswell, 2007). The researcher of the present investigation has been involved in, and has conducted numerous qualitative research studies, but must disclose that she identifies as a post-positivist who applies a scientific or quantitative lens to her qualitative work. Her post-positivist approach involves logical steps and rigours methodology (Creswell, 2007). This researcher is an able-bodied, heterosexual female who has no first-hand experience with the phenomenon. She has, however, been researching in the area of SCI for twelve years during which time she has worked directly with individuals living with the injury. She has previously gained insight into the experience of sexuality for women with SCI through phenomenological investigation.

Due to the fact that the psychological and emotional impact of SCI on sexual functioning for men has certainly been understudied, a descriptive, exploratory qualitative approach should be the first step in obtaining a better understanding of this phenomenon. The goal of this study is not to predict, but to receive information.

Delphi Method

The Delphi Method is a consensus tool and group facilitation technique. The Delphi Method systematically and interactively gains the opinions of an expert panel of judges comprised of informed individuals to reach an agreement on relevant topics (Hasson, Keeney & McKenna, 2000; Shah & Kalaian, 2009). This is accomplished through a series of questionnaires in which each round is informed by the results of the previous round (Hasson et al., 2000). Controlled feedback involving an anonymous summary of responses is fed back to the panel to enable them to review their responses in comparison to the responses of other panel members. They are then given multiple opportunities to change their responses to facilitate movement towards a consensus (Hasson et al., 2000; Powell, 2003; Skulmoski, Hartman & Krahn, 2007).

While the Delphi Method was originally applied in the business world (Skulmoski et al., 2007), it is now commonly used in health research (Hasson et al., 2000). Thangaratinam and Redman (2005) noted that between 1969 and 2005, there were over 1400 publications in healthcare research using this method.

The Delphi Method is appropriate for use in areas of uncertainty, where there is insufficient or contradictory information and where knowledge is incomplete (Hasson et al., 2000; Powell, 2003; Skulmoski et al., 2007), such as sexuality and SCI. The anonymity of the Delphi Method will facilitate information exchange of personal and sensitive topics while avoiding the negative dynamics associated with group discussion including status, overbearing personalities and pressures to conform to group ideals (Thangaratinam & Redman, 2005). Based on the above information, the Delphi Method is an appropriate technique to understand issues of sexuality in a larger group of men with SCI and healthcare providers.

Rationale

Given the holistic nature of sexuality, psychosocial, psychological and emotional components of sexual rehabilitation are beginning to elicit attention. However, because SCI has been predominantly viewed as a

physical experience (Romeo et al., 1993) and has been largely medicalized to emphasize the treatment of a disorder, the psychosocial aspects of sexuality have received inadequate consideration (Sunilkumar et al., 2015).

Specifically, there has been a lack of qualitative research to address the subjective experiences and sexual well-being of individuals living with a chronic disease or disability (Verschuren et al., 2010). While addressing psychological and emotional concerns resulting from SCI in the context of sexuality may be just as important as physical rehabilitation (Derry et al., 1998; Giuliano et al., 2008), broader meanings of sexuality are rarely explored from the perspective of the individual living with SCI (Basson et al., 2003; Dahlberg et al., 2007; Leibowitz & Stanton, 2007) or from the perspective of the healthcare providers who work with this population. Furthermore, there is a lack of resources regarding psychological aspects of sexuality after SCI (Peter, Muller, Cieza & Geyh, 2012).

Inconsistencies exist between the rehabilitative needs of individuals living with SCI and healthcare provider perceptions of their patients' rehabilitative needs. This includes sexual health which has consistently been reported as a top priority of patients, but continues to be under addressed by healthcare providers (Simpson et al., 2012; Zhang, Sherman & Foster, 2020). Education for healthcare providers about sexuality and SCI is important as an untrained professional may unintentionally promote negative misconceptions and myths which can have a detrimental effect on the societal-view and self-view of an individual living with SCI (Elliott, Hocaloski & Carlson, 2017). Additionally, healthcare providers need to have an accurate understanding of how men with SCI view sexuality so they are able to support them.

Understanding the psychological and emotional aspects of sexuality for men after SCI is vital to enhancing sexual education resources and best-practice guidelines. Assessing the extent to which the psychological and emotional concerns of sexuality of men with SCI are aligned with the perceived concerns of their healthcare providers will facilitate patient-provider conversations about sexuality

(Zhang et al., 2020), aid those with SCI in their sexual readjustment post-injury and contribute to improved overall QOL for this population (Anderson et al., 2007; Cramp et al., 2014).

The objectives of this dissertation are: a) through phenomenological interviews, examine the experience of sexuality for men after SCI with an emphasis on psychosocial, psychological and emotional aspects, b) to use the Delphi Method to explore prominent themes with a larger sample of men living with SCI, and c) to use the Delphi Method to examine the experience of sexuality for men after SCI from the perspective of healthcare providers who work with this population. Discrepancies between patient and healthcare provider perspectives of sexuality after SCI will be highlighted to identify gaps where patient-provider understanding need to be aligned.

CHAPTER 2: EXAMINING THE PSYCHOLOGICAL AND EMOTIONAL EXPERIENCE OF SEXUALITY FOR MEN AFTER SPINAL CORD INJURY

The work in this chapter reflects the work of the candidate with minimal contribution, suggestion and editing from the supervisor and the committee. A copy of the published version is included in the appendices.

Abstract

Sexual rehabilitation for men after spinal cord injury (SCI) has focused on physical challenges and neglected psychosocial factors. Utilizing a descriptive phenomenological approach, the lived psychological experience of sexuality was described for six men (age 24-49) with complete or incomplete SCI (C4-T12; <1 year to 29 years post-injury) who participated in one in-depth, standardized, open-ended interview (68-101 minutes). Participants described the emergence of a new perspective of sexuality placing less emphasis on any one physical act and more importance on emotional factors. Understanding the evolving meaning of sexuality for men after SCI is imperative for delivering effective sexual health information.

Introduction

Sexuality is a basic human need that is vital for achieving satisfaction with one's overall quality of life (QOL) (Reitz et al., 2004). Society has strong ideals of what sexuality is and who is allowed to participate. Sex is viewed by society as a privilege of the young, beautiful and non-disabled, thus suggesting that individuals with disabilities, including spinal cord injury (SCI) are not sexual (Sakellariou & Sawada, 2006). Individuals with SCI are told they must disregard their inherent sexual desires that are human in nature, and abandon that part of themselves (Herson, Hart, Gordon & Rintala, 1999). However, sexual adjustment after SCI is not solely dependent on genital function or level of injury (Siösteen et al., 1990). Despite changes in mobility and sensation, sexual desires may be unaltered and sexuality continues to be important to many individuals after SCI (Sakellariou & Sawada, 2006; Siösteen et al., 1990). Kreuter and colleagues (1996) suggest that sexuality is not synonymous with genital function, and that the

emotional and sensual dimensions of sexuality may compensate for physical limitations resulting from SCI.

In terms of sexuality for men after SCI, literature has focused primarily on physical aspects of sexuality such as obtaining and maintaining an erection, and successful ejaculation. Emphasis has been placed on the measurement of these physical indicators of sexual performance (Sunilkumar et al., 2015), and the psychological aspects of sexuality have been largely neglected for men with SCI (Basson et al., 2003). Nevertheless, sexuality is multifaceted and due to changes in function and sensation, the psychosocial aspects may be more important than the physical factors for achieving satisfaction with sexual life in this population (Kreuter et al., 1994; Siösteen et al., 1990). General anxiety, performance anxiety, negative self-concept, feeling sexually unattractive, emotional distress, fear of rejection, depression, feelings of sexual inadequacy, lack of confidence and self-doubt regarding sexuality after SCI may have a more profound negative affect on sexual adjustment than the actual genital dysfunction (Low & Tunku, 2000; Siösteen et al., 1990;) and may lead to avoidance of sexual activities (Kreuter et al., 1996). Therefore, addressing the psychological and emotional concerns resulting from SCI, especially in the context of sexuality, may be just as important as physical rehabilitation (Giuliano et al., 2008). This study aimed to examine the lived psychological and emotional experience of sexuality for men after SCI.

Materials and Methods

Phenomenology

An inductive and exploratory qualitative approach was employed. Utilizing Giorgi's descriptive phenomenological method (Giorgi, 2009), an in-depth examination of the experience of sexuality for men living with SCI was conducted to explore their lived experiences. The goal of this study was not to predict, but to receive information.

Participants and Recruitment

Phenomenology requires the participants have personal, lived experience with the phenomenon under investigation (Patton, 2002), and recognizes that only certain individuals will be able to provide information that is useful and relevant for describing the phenomenon. Therefore, purposive sampling was used to select participants based on the information they would be able to provide (Carpenter & Suto, 2008). This resulted in detailed, information-rich descriptions of experiences from men who had firsthand knowledge of sexuality after SCI (Creswell, 2007). Phenomenological investigations generally involve a small number of participants (Carpenter & Suto, 2008; Polit & Hungler, 1995) and focus on meaning, richness and depth of the data that are uncovered rather than sample size (Liamputtong, 2009). Six participants took part in this study which falls within the recommended guidelines for this type of investigation (Patton, 2002; Polit & Hungler, 1995). Individuals were eligible to participate if they were male, between the ages of 18 and 50, living in Canada with a SCI of any level or classification and were able to communicate in English. Participants were recruited via posts on relevant social media platforms, by word of mouth and through support from Spinal Cord Injury Ontario.

Interviews

Pseudonyms were chosen by each of the men who participated in this study, and they were referred to by these names throughout the entirety of the investigation. Each participant completed one confidential, in-depth telephone interview lasing between 68 and 101 minutes in length (mean time 81 minutes). Interviews followed a standardized, open-ended approach combined with interview guide approach (see Appendix E for complete interview guide) ensuring the same topics were addressed with each participant while also allowing for further investigation into new and relevant topics that arose but were not planned for or not anticipated (Patton, 2002). The main interview questions can be found in Table 1 and included the six types suggested by Michael Quinn Patton: demographic, experience/behavior, knowledge, sensory, feeling/emotion and opinion/value (Qualitative Research & Evaluative Methods, 3rd ed, 2002), and probing questions were used to delve deeper and obtain additional information regarding certain topic areas. Interviews were audio recorded using a Sony ICD-PX370 digital voice recorder and were

transcribed verbatim. Field notes were recorded during each interview. Ethical approval was obtained from the York University Research Ethics Board and the Brock University Research Ethics Board.

Table 1 - Main Interview Questions

Question Number	Main Interview Guide Questions
1.	Can you start by telling me a little bit about yourself and your spinal cord injury?
2.	What is the meaning of sexuality to you?
3.	How has your spinal cord injury impacted your sexuality and/or sexual function?
4.	Describe a time after SCI when you felt sexually satisfied (or describe a situation that would make you feel sexually satisfied).
5.	How would you describe any body issues that you are concerned about when participating in, or thinking about participating in sexual activities?
6.	How has your spinal cord injury affected the way you see yourself? How has this affected your sexuality?
7.	Tell me a story about a time or situation when your SCI affected your sexual life.
8.	As you talk about and reflect on your sexual life after spinal cord injury, what types of feelings and emotions are you experiencing?
9.	What resources have you used or accessed (books, pamphlets, videos, support groups, etc.) to help with adjusting to your sexual life (sexuality, sexual function) after SCI?
10.	Is there anything that we didn't talk about today that you would like to discuss now, or is there anything that you would like to add to our conversation?

Analysis

Data were analyzed by means of ongoing and constant comparison to determine how one transcript may convey a message about the others. This was achieved using Giorgi's method and adhered to the following procedure: transcription, read and jot, meaning units, first transformation, specific descriptions, general descriptions, revelatory phrases and emerging themes (Giorgi, 2009). Analysis began with unique, or within-case orientation where each transcript was examined as its own case. This was followed by a cross-case analysis and individual cases were compiled to examine the phenomenon across various contexts and relationships, and to uncover the prominent themes and patterns that emerged between them. Data were analyzed independently by two researchers and discussed until a consensus was met regarding emergent themes, and a reflective journal was kept throughout the process to track decisions (Carpenter &

Suto, 2008). To stay close to the data, themes were supported by direct quotations from the participants' transcripts. The emerging themes represent the lived experiences and prominent ideas of these particular men regarding this particular phenomenon.

Results

Six men with complete or incomplete SCI (C4-T12) between the ages of age 24 and 49 participated in this study. Participants were <1 year to 29 years post-injury. All of the men identified as heterosexual. Four of the men were married, one was in a relationship and one was divorced. Three of the six men had children. Of these men, two had children prior to their injury and one had children after his injury. Table 2 outlines demographic and interview characteristics for each participant.

Table 2 - Participant and Interview Characteristics

Participant	**"Joe"**	**"Elliott"**	**"Will"**	**"Steve"**	**"Paul"**	**"Peter"**
Interview Length	81 min	101 min	83 min	67 min	86 min	68 min
Age	24	32	45	49	49	47
Injury	C7 Incomplete	C4 Incomplete	T9 Complete	C4/C5 Incomplete	T12 Incomplete	T6 Complete
Years Post-Injury	6 years	15 years	28 years	29 years	7 years	7 months
Sexual Orientation	Hetero-sexual	Hetero-sexual	Hetero-sexual	Hetero-sexual	Hetero-sexual	Hetero-sexual
Relationship Status (current)	In a relation-ship	Married	Married	Married	Divorced	Married
Relation-ship Status (at injury)	In a relation-ship	In a relation-ship	Single	In a relation-ship	Married	Married
Participation in Sexual Activities Prior to Injury	No	Yes	Yes	Yes	Yes	Yes
Participation in Sexual	Yes	Yes	Yes	Yes	Yes	No

Activities Post-Injury						

Themes:

The men in this study acknowledged stereotypes and societal beliefs pertaining to sexuality, masculinity, disability and attractiveness and recognized that as a result of their SCI, they no longer conformed to these norms. The men expressed the importance of adapting their own beliefs regarding these topics in order to find acceptance of themselves in *'a world that is not all that accepting.' -Will*

Elliott: "Definitely I've fallen into stereotypes of what disability and sexuality were like until I started to investigate it more and realized that they're not entirely true. Every part of my body and the way in which society views the norms of what a body should look like. I think I'm constantly going back to it thinking that there is something inherently wrong with my body. …facilitating an erection can be tricky and it's kind of the main part of many peoples' view on what sex should look like. So if you don't have a really great erection then obviously you're kind of failing in one very important part of what many partners find very important."

1. Changing Perspective of Sexuality

When asked to describe the meaning of sexuality, all of the men in this study described feelings of intimacy and connection with themselves and/or their partner on an emotional level. The men stated that being physical and/or having penetrative sexual intercourse may play a role in sexuality, but revealed that the physical aspects of sexuality were "just a tiny little part of it." *-Paul*

Joe: "Meaning of sexuality? I guess how one feels or expresses their intimate feelings. …it's not all about sex at all. For me it's more emotional."

Will: "[Sexuality is] the intimacy between two people. …it's not defined by one particular act [intercourse]. Sexuality is everything from the intimacy between two people, their interactions, the different ways that they arouse each other and the different ways that they inspire each other in those intimate moments."

Steve: "[Sexuality is] being connected with yourself emotionally and physically. And sexuality is also about being connected with your partner in that same emotional type of way. Not just in the physical sense."

This portrayal of sexuality differs from the description of sexuality these men thought they would have provided in the past. Prior to SCI, the men thought of sex and sexuality in a physical sense with emphasis on penetration and intercourse. They referred to this as the "traditional" view of sexuality. Post-injury, physical factors became less important due to decreased sensation and decreased ability to trigger an erection or successful ejaculation, as well as decreased physical function and mobility to perform various sexual activities. The men explained that sex cannot be defined the same way it was prior to injury, and that the meaning of sexuality was an evolving concept that changed and expanded over time and with new experiences.

Will: "It's a long road getting to that point where you get past what would be considered a traditional method [of sex], however you want to define it. It becomes about things that you may not have realized were quite as important before. It's something that yes, you have to define it in a different way, you don't really have a choice. You can't try to define it [sexuality] by the same way it was pre-injury."

Elliott: "I think before my spinal cord injury, the way I would think of sexuality was penetration. And that was basically it. I just wasn't really interested in a whole lot of stuff other than that. Right now, I'm more leaning towards the non-penetration side of a variety of sexual activities."

Will: "It [SCI] took the focus off of the one traditional act that everyone comes to think about when it comes to sexuality, and moved it to other places, and thinking about it in other ways. And sometimes it actually doesn't have to do with any one act or anything. It definitely becomes more emotional."

As the men let go of the idea of sex as a purely physical, penetrative experience, they became more appreciative of the psychological and emotional side of their sexual relationships, and experienced sexuality in a new way. One participant explained that he was able to reach a deeper level of intimacy which he felt he would have been unattainable without his injury. He supposed the focus on physical factors of an able-bodied person would actually inhibit their ability to reach an understanding of intimacy on that level. In his opinion, sexuality was more fulfilling within this perspective than it was prior to injury.

Steve: "Sex is way different because I focused solely on genitalia [before SCI]. It took a while at the beginning because you think of sex from a physical standpoint. You don't think from an emotional standpoint. It [SCI] just opened my mind to a whole different level of sexuality because guys are normally not taught to be emotional in any way or in contact with your own sexuality that way. And it's much more fulfilling in my opinion to be connected with your partner emotionally than it is just the physical aspect. I honestly probably don't think [I would have gotten to this level of sexual fulfilment without SCI] because I would have been concentrating so much on the physical aspect of it. I don't know if that would have gotten in the way of understanding that level of intimacy. The physical aspect of feeling your genitalia and you know, wanting to have that physical release is actually in the way of your emotions. You really have to look at it from a different perspective. And you can't look at it from your typical male

perspective… it's not just about getting off. It's about being connected. And it [SCI] really taught me that. Because that physical release, you have to find it from a different avenue of connection. And it's more fulfilling being this way than it is being the other way."

Men who had not embraced this new perspective of sexuality struggled to find satisfaction within the traditional framework of sexuality, and in some cases, this led to decreased interest and participation in sexual activities. When asked to describe a time since his injury when he felt sexually satisfied, the most recently injured participant (<1 year post-injury) who was focused on recovery and regaining "normal" function and sensation, reported that he was unable think of a time when he had been sexually satisfied post-injury. This is in contrast with the men who had embraced the new perspective of sexuality, focusing less on physical function and sensation, and placing more emphasis on intimacy and emotional connection.

Furthermore, as a result of being unable to *feel* the body or pleasurable sexual sensations, including climax, in the same way they did prior to injury, all of the men in this study reported that they now placed more emphasis on their partner's sexual satisfaction. Many of the men stated that a great deal of their own sexual satisfaction came from their partners' satisfaction, and through their partner, they, themselves were able to feel satisfied in a sexual sense. For the majority of these men, this differed from their perspective of sexuality prior to injury as they had tended to be more concerned about themselves in their past sexual situations.

Elliott: "[Before SCI] I was just basically thinking about myself a lot of the time. And I think after my spinal cord injury I've also learned that your partner is very, very important to think about. And you can have a positive experience from your partner's reaction as well. [Sex] definitely doesn't feel the same as what it used to feel like, so I think it's very difficult for me to only focus on myself when it's very difficult for me to get to that point [climax] so I tend to focus I think more so on my partner."

Steve: "That's how I get pleasure out of it now. Pleasuring my partner. That's what gets me excited. That's where I get my enjoyment from. It's that my partner is being pleasured."

Generally speaking, participants conveyed a continued importance of sexuality in their lives post-injury. The men explained that satisfaction with their sexual lives was necessary for improving other physical and psychological health issues, and that sexual satisfaction was vital for improving their outlook on life and overall QOL.

Elliott: "I definitely know that I am a little bit more frustrated because that part of my life [sexual] hasn't been as adequate or what I was hoping it would be. It definitely makes it my mood a lot worse. …my thoughts about myself, and just life in general is not always the greatest, but they probably would be if my sexuality was a little bit more positive."

2. Changing Perspectives of Masculinity

Participants in the current investigation admitted to taking part in, or at least being aware of, society's beliefs about the meaning of masculinity which they characterized using terms such as *strength, dominance* and *sexual conquests*. The men also acknowledged that SCI affects many of the traditional measures of masculinity in both activities of daily living as well as in a sexual sense. Again, the men in this study were able to expand their views of masculinity and redefine the concept. By placing more emphasis on the strength required to allow others to support them, the nobility in being there to support those close to them, the strength in being vulnerable, showing emotions and exposing one's true self rather than focusing on strength in the physical sense that is often associated with masculinity, there was acceptance that they were no less of a man as a result of the injury. It was also noted that sex can be experienced and enjoyed in many ways, and having the man play the dominant role in a sexual setting is not the only approach.

Elliott: "…before my injury [I had] very specific stereotypes in my head where the man was supposed to be the strong one and the man was supposed to be the dominant persona, especially like in a sexual sense. Now, after my injury, I really can't be the physical, dominating [person] in a sexual relationship and it plays into the way I actually feel about sexuality. And I don't think there is any general way to look at how a man or a woman should act in this situation. I think everyone enjoys [sexuality] in a bunch of different ways."

Will: "I don't believe in the old toxic masculinity view of things. I don't judge myself as a man by my conquests. To me, being a man is just simply what you are to your friends and family, to the people that you care about. It's about being there to support others, it's about being there to let them support me if and when I need it. Now that probably has changed quite a bit from prior to the injury because, yes, I did definitely judge myself by other people's achievements, how many women had I dated etc. Yeah, I could have very much fallen into that category. But these days I don't judge myself as a man by that aspect at all. I do find myself occasionally falling into that trap because things [penis/ body] don't work as the average man thinks they should. That does occasionally get you a little depressed, but I do try to get myself out of that by realizing it hasn't changed who I am as a person."

Steve: "'Oh suck it up, don't cry, men don't cry.' Yeah, we do, and you should. And you should express that. And I find that I'm more of an emotional person now. And that's a real man. The real man is someone who can show their emotions, not just anger and other things."

3. Changing Perspective of Disability

Spinal cord injury affects how an individual is viewed within society, and the men suggested this is because SCI is a visible disability. The men felt the injury was the first thing people saw when they

looked at them and suspected that some people may not be comfortable interacting with them because of the injury. The men have felt misunderstood when people assumed they must have a mental disability as well as a physical limitation. They have felt looked at as a patient more than a person, viewed as a science project, and they have felt that people look at them with pity. The men explained that for some people, the SCI is not something they can look past. This is challenging when meeting new people in general, and also when trying to meet a new potential sexual partner. The men in this study described the importance of finding a partner who was willing to look past the injury, and who was open to getting to know them as a person.

Will: "I recognize and acknowledge the fact that when you're meeting new people for the first time, the chair is the first thing that many of them will see. Some people can't get passed it. It's [SCI] always there in one way or another. People are always wondering how they can help me, and if I need help."

Joe: "You always feel like people are looking at you with pity, like they feel bad for you. And it's sometimes difficult to get them past that point. You always feel like they're looking at you as sort of a poor person that has to be looked after. So, a lot of people have this misconception that when I say wheelchair people think mental disability or that I can't do anything below my head, stuff like that. It can be tough. You can't really blame them for that. They just don't have any experience previously with people in wheelchairs."

Joe: "Being in the hospital, I've been looked at as a patient more than a person for three years. Everybody would look at me as a person with a spinal cord injury, like, 'he's just a patient. He's a science project.' So, once I was able to meet someone who looked at me as a person rather than a patient, that just made me feel completely so much better."

Steve: "…those online dating sites. I was trying to go out there with a generic profile, so you get all your physical attributes and they call you and then [after finding out you have a SCI] they're like, 'oh, yeah never mind…'"

4. Changing Perspective of Attractiveness

Society has beliefs about what an ideal body is supposed to look like, and the body of a man living with SCI may not encompass that vision. Participants in this study revealed that after their injury, they felt as though no one would find them attractive. The men questioned their own appeal to another person and felt they would have to settle in terms of the partner they would end up with. This led to an enhanced fear of rejection and avoidance of approaching new people, thereby resulting in feelings of loneliness and depression.

Elliott: "At that point I had been fairly certain that like, like no one would find me attractive because of my disability and because of my spinal cord injury. I just kind of assumed that wasn't something that was going to happen."

Joe: "It takes me back a little bit to the beginning of my injury when I thought everything was over and that I'd never be able to find anyone that's attracted to me. [At first] you just don't feel like it's going to be possible to find a partner or that you'd have to lower your standards to the point where you're not even attracted to the person. It triggered depression. There are other parts of the injury that cause that too, but mainly it was a feeling of loneliness."

Elliott: "I just didn't really feel comfortable approaching anyone. It's definitely something that's very difficult for someone with disabilities. I think there is constantly a fear of rejection. I think it's a lot more

now than it was before my injury. It still would be just very, very difficult for me to actively engage in a relationship because of self-doubt."

One participant described a specific situation where he felt his SCI affected the way women viewed him and his level of attractiveness as a potential partner:

Steve: "When I sit in my car, you can't tell I'm in a wheelchair. I'm a good-looking guy, and all they can see is my face and my smile. I get out of my car, and they turn their head away. I'm the same guy you just looked at, like looks-wise, but now I'm in a wheelchair. So, what's the difference?"

Men described specific body image issues they experienced as a result of SCI which included a loss of muscle mass, a larger stomach, pressure sores, spasticity, restrictions on the type of clothing they could wear, bladder and bowel issues, always being in a seated position and having a flaccid penis. The men compared their current bodies to their bodies prior to injury, and described the difficulty and frustration in not being able to do anything about it. Due to the fact that they could not be as physically active as they were prior to injury and could not engage certain muscles to work, they expressed a sense of hopelessness.

Steve: "Now I have a quad gut (larger stomach due to inability to engage core muscles) and my arms are skinny, my legs are skinny. Like I said, I was an athlete. I was fit. That is hard for body image."

Will: "I've got the tummy, my [legs] have withered, and unfortunately because of the nature of the injury, with the loss of strength in muscle tone of my abdomen there's a lot of weight. It's not even weight, it's more just flab that has appeared just because you can't do proper exercises in that region, the muscles don't work all that much and I've gained myself a belly."

Changes to body image also enhanced their fear of rejection by a potential partner and heightened avoidance behavior.

Elliott: "Just initiating any type of [sexual] activity with anyone else was terrifying and I just didn't really want to get into it. I just found a variety of parts of my body unattractive and I felt that if I got into a situation with anyone else, they would also find me unattractive."

Joe: "I was at my lowest point in confidence. Confidence in myself. Feeling that people wouldn't be attracted to me, or confidence in approaching people, or you know, so-called 'making a move' or anything like that really."

One participant went on to discuss how these issues with body image affected his feelings about himself, his confidence, his self-esteem and how these insecurities caused him to fall back into the negative self-thoughts he had been able to overcome prior to his injury. Ultimately, he was led to question his appeal to potential partners.

Will: "It's hard not to judge myself, and that affects your view of yourself. I thought I had gotten over them [my insecurities] before the injury took place because I was more confident with myself. I became successful to a degree in life, and then this happens, and then you start questioning everything again. When you look at yourself, and unfortunately because you're in a seated position all the time, it makes things look that much worse than if you were able to get into a standing position. It reduces what you see as your own appeal. When you layer that on top of the fact that things don't work [penis], umm, you start to, you can't help but question what your own appeal is. What would it be that would bring people to you to see you that way [as a potential sexual partner]?"

Participants believed they were doubly disadvantaged as consequences resulting from SCI left them feeling unattractive, as well as feeling disabled in the sense that the body, and specifically the penis, did not function the way they believed it should. While able-bodied men may feel insecure about the size of their penis due to society's obsession with its appearance, men with SCI may feel an added insecurity in this regard due to an inability to achieve erection. When participating in sexuality activities, if the penis is flaccid, it may appear smaller than it would if it were erect adding another dimension of concern for these men.

Joe: "With men obviously there's always an obsession with, everyone constantly talking about the size of your penis. That's the body image thing for men. There is always a nervousness about that, even so like it may not be small or whatever, but when you're not using it sexually all the time or getting erections all the time without medication they usually shorten because you're not exercising that stretching right? So that's definitely a concern, and always is."

Participants acknowledged the high probability that all men, able-bodied or not, are likely to have concerns with body image. However, they explained that men with SCI have to deal with all the concerns any man would have to deal with, as well as an added layer of concerns that are directly related to the injury. Two participants explained that SCI had escalated the negative body feelings they experienced prior to injury, with the injury making them more intense.

Joe: "I would say [men with SCI have] the same body issues [as able-bodied men], probably a little bit worse because you're sitting down all the time. And you're limited in what kind of clothing you can wear. Or I'm limited, by like, pressure sores, so I can't wear jeans. Umm, yeah, it's a different set of body image issues but I think everyone has them to an extent. Able-body or not."

Elliott: "Even before my injury I always had a hard time with various parts of my body. But they did emphasize after my injury. [SCI] definitely made a lot of my body perceptions a lot worse than they were before."

Similar to the concepts of sexuality, masculinity and disability described above, one participant suggested that people need to change their views of what they think they are looking for in a partner, expanding beyond the physical and reaching into the more meaningful, deeper connections. He explained that people put a lot of emphasis on physical attributes, but that personality and connection with a virtuous person are more important than their superficial traits.

Steve: "... people who want to be with you want to be with you regardless. So when you realize that, you are more confident. Sure, there might not be as many people you come across that want to give you that chance, but then you weed out the bad people. What does 6 foot 3 have to do with anything? Nothing. Find a guy that treats you nice. Find a guy that will be kind. And will listen. Like, a guy that has six pack abs and huge muscles, and biceps, and everything like that, you really think he's deep? Do you really think he's gonna care about your needs? Some guys might. I'm generalizing again. Some guys might, but few and far between. Find connection, and you'll be so much more fulfilled. If people would realize that, they would be so much happier."

Discussion

Sexuality and sexual function are of top priority for individuals living with SCI (Anderson, 2004) and play an important role in their overall rehabilitation (Sheel et al., 2005). Literature suggests that over 80% of individuals with SCI feel that their injury has altered their sexual sense of self, and that improvements to sexual function would improve their overall QOL (Anderson et al., 2007). This is consistent with the

present findings as the men in this study generally felt that if they improved their sexual lives, they would improve their mood, they would feel happier and the quality of their lives would be better overall.
The top two areas of research for men regarding sexuality after SCI are erectile dysfunction and ejaculatory dysfunction (Anderson et al., 2007). Although effective treatments for erectile dysfunction and anejaculation exist, the psychological and emotional consequences of SCI on sexuality for men remain understudied (Dahlberg et al., 2007). Sexuality is a complex physical and psychological phenomenon, and through a description of their own lived experiences, participants in this study identified an evolving meaning of sexuality in which psychosocial factors were vital to increasing sexual satisfaction. Participants generally, but to differing degrees, described the emergence of a new perspective on sexuality placing less emphasis on physical factors, specifically penetration, and more importance on psychological factors including intimacy, connectedness and emotional closeness with their partner. Men who reported embracing this perspective of sexuality reported a deeper and superior sexual experience and level of intimacy, some even more so than prior to injury, whereas the participant who had not adopted this perspective reported lower levels of sexual interest and satisfaction. This is consistent with a previous study of 134 able-bodied individuals that found greater levels of intimacy were linked to higher levels of sexual desire (van Lankveld, Jacobs, Thewissen, Dewitte & Verboon, 2018). Furthermore, Štulhofer and colleagues (2014) that found sexual satisfaction was contingent on intimacy, and similarly, a study by Pascoal and colleagues (2013) found emotional intimacy to be the best predictor of sexual satisfaction in individuals with sexual arousal issues.

Masculinity was the second emerging theme and is a social construct that is closely linked to sexuality. Its clearly defined expectations may have a detrimental effect on men after SCI (Esmail et al., 2010). Boys are taught the possession, size and use of their genitals, as well as initiating sexual activity and possessing a high sexual drive are indicators of manhood (Burns et al.,2010). Masculinity has been described in the literature, and by the men in this study, using words such as physical, athletic, assertive, breadwinner, dominant and sexual prowess, all of which may be affected by erectile dysfunctions and other physical

limitations resulting from SCI. As a result, appropriate gender roles and sexual identity may be disrupted (Sakellariou & Sawada, 2006) making it necessary for the men in this study to alter their perspectives on the meaning of masculinity. Men focused on non-physical strengths, specifically the strength that comes from being a good person who is in touch with their feelings and emotions and who supports, and is supported by, those around him to represent the character of a '*real man*.'

The third theme involved perspectives on disability. The men revealed that they often felt as though people saw only the disability when they looked at them and recognized the injury was not something that everyone would be able to move past. Participants with SCI have questioned whether the attention they received from others was out of curiosity about the disability and pity, or because of interest in them as a person. In most cases, participants assumed it was the former (Potgieter & Khan, 2005). Many myths exist about people who live with a disability, and due to a general ignorance about what it means to live with SCI, people may feel uncomfortable interacting with this population and may also have an assumption that they are asexual (Potgieter & Khan, 2005). Working to educate society about what it means to live with a SCI may improve social opportunities to engage in sexual relationships post-injury.

The final theme considered physical attractiveness. An ideal body may be thought of as one that stands, and for a man, it may also include a body that is strong, lean, muscular and athletic (Blond, 2008). These ideas are reinforced in society where exposure to the male body in its ideal form and as a sexual object is abundant (Blond, 2008), making it difficult for men with a disability to escape this perspective. Blond (2008) found that exposure to idealized male bodies in advertisements and other forms of popular culture had a significant negative impact on body satisfaction, specifically for those with lower levels of body satisfaction which may include those living with a disability. Men with disabilities are taught that their bodies are unattractive because they do not conform to the socially accepted standards of an ideal male body (Potgieter & Khan, 2005), and the men in this study were aware of the ways in which their bodies deviated from this. Physical consequences of SCI described in this study included weight gain, a larger

stomach, muscle atrophy, spasticity, pressure sores, flaccid penis, being in a seated position, not being able to wear certain types of clothing and issues with the bladder and bowel. As a result, the men felt unattractive and questioned their own appeal to a potential partner. Consistent with work by Potgieter & Khan (2005), the men experienced negative emotions including loneliness and depression as a result of avoiding opportunities to meet new potential partners due to a heightened fear of rejection.

Addressing the issues identified through this investigation may lead to improvements in the lived sexual experiences for men after SCI. Suggestions include educating healthcare providers on the changed perspective of sexuality for this population so that sexual education may be consistent with the interests and priorities of the patient. Healthcare providers should be aware of the stigmas surrounding sexuality and disability, as well as their own biases regarding the topic which may influence the information they provide, and which patients they choose to provide this information to. The findings of this study highlight and further support a need for the use of a biopsychosocial approach when addressing sexuality in SCI rehabilitation (Elliott et al., 2017; Pieters et al., 2018), allowing for holistic consideration of this multifaceted and complex phenomenon, integrating both the physical and psychological/ emotional aspects of sexuality.

This study recognizes its possible limitations. Participants varied in terms of injury level and classification which provided a broad view of the issues that exist for this population. While this approach was valuable for capturing the core experiences of this phenomenon across contexts and identifying factors of particular interest (Patton, 2002), it is possible that the severity of injury may affect one's perspectives of sexuality. However, the themes presented in this paper represent broad social constructs and there appeared to be no notable differences based on injury level or classification. Perspectives were influenced more by time since injury and past experiences (positive or negative). Present findings describe the lived experiences of these particular men at this particular point in time and may not be generalizable to larger populations or other instances in time. Interviews were conducted by the primary

researcher who is female, and it may be challenging for men to be forthcoming with information about their sexuality with a researcher of the opposite sex. However, it has been reported that men are equally, if not more likely, to reveal concerns related to body image with a female researcher (Yager, Diedriches & Drummond, 2013) and that a female interviewer is generally preferred. Possible explanations may be related to social norms and expectations that women would naturally be more sympathetic (Pollner, 1998) and less critical (Derlega, Winstead, Wong & Hunter, 1985). Additionally, all of the participants in this study identified as heterosexual and the voices of these particular men may not represent those who identify with other orientations. Future work should consider other sexual preferences.

Men disclosed they had been challenged with overcoming the stereotypes assigned to them by society, as well as their own pre-injury ideas regarding the constructs of sexuality, masculinity, disability and attractiveness. These constructs play a role in one's overall sexual experience, and Potgieter and Khan (2005) concluded that socially constructed attitudes seemed to limit opportunities to express sexuality for individuals living with SCI more than their disability. Men with SCI may be aware of their deviations from societal norms and may benefit from learning to "reject the inflexible, discriminatory conventions rather than themselves" (Potgieter & Khan, 2005). The men in this study developed an adapted understanding of four dominant societal beliefs, moving beyond traditional definitions and embracing new and expanded meanings that were more consistent with life after SCI.

An updated and holistic understanding of how men with SCI describe sexuality is important for the development of relevant information and effective interventions that may have a positive impact on their sexual experiences and contribute to an improved overall QOL.

CHAPTER 3: SUPPORTING SEXUAL ADJUSTMENT FROM THE PERSPECTIVE OF MEN LIVING WITH SPINAL CORD INJURY

The work in this chapter reflects the work of the candidate with minimal contribution, suggestion and editing from the supervisor and the committee. A copy of the published version is included in the appendices.

Abstract

Using a descriptive phenomenological approach, this study explored the lived experience of sexuality for men after spinal cord injury (SCI) and described the current state of tools and resources available to assist with sexual adjustment from the perspective of men living with SCI. Six men (age 24-49 years) with complete or incomplete SCI (C4-T12; <1 year to 29 years post-injury) in Ontario, Canada participated in one individual, in-depth, standardized, open-ended interview (68-101 minutes). Analysis was conducted using Giorgi's method, and involved within case analysis followed by cross case analysis. All participants reported that resources available to support sexual adjustment after SCI were inadequate, and the majority of men felt their healthcare providers lacked knowledge regarding, and comfort discussing sexuality after SCI. Men reported sexuality was not a priority of rehabilitation centres and felt that healthcare providers did not understand the importance of addressing sexuality. Existing resources were described as too clinical and not necessarily relevant given changes in sensation and mobility post-injury. Participants provided recommendations for the effective delivery of relevant sexual education information. To improve quality of life for men after SCI, suitable resources must be available to support sexual rehabilitation post-injury. Future research should focus on developing strategies to facilitate discussions about sexuality between individuals with SCI and healthcare providers, and on developing resources that are effective and relevant for these men.

Introduction

More than 86,000 people in Canada live with a spinal cord injury (SCI), half of which reside in the province of Ontario (Noonan et al., 2012; Jim et al). While SCI will affect many body functions and sensations, a SCI does not eliminate sexual feelings or the need for physical and emotional sexual intimacy (Sharma et al., 2006). Sexuality and quality of life (QOL) are interwoven and reinforce one another, and an active and satisfying sexual life after SCI is associated with improvements in overall adjustment and QOL (Siösteen et al., 1990; Pieters et al., 2018). A study by Anderson and colleagues (2007) found that 83.2% of participants felt their SCI had altered their sexual sense of self, and 82.9% felt that improving sexual function was important for improving QOL. Despite the importance of sexual health and sexual education for individuals after SCI, there is an unmet need for sexual rehabilitation information, as well as numerous challenges for patient-provider discussions regarding sexuality (Low & Tunku, 2000; Sunilkumar et al., 2015). All of the participants in a study by Basson and colleagues (2003) felt they had received inadequate guidance regarding sexuality from their healthcare providers. Patients and healthcare providers alike have reported difficulties regarding sexual education for individuals with disabilities. Patients reported that healthcare providers lacked knowledge when it came to sexuality for people with disabilities and felt their healthcare providers were too shy to have the discussion with them (Low & Tunku, 2000). From the healthcare provider perspective, barriers included a lack of time, lack of knowledge, lack of clarity regarding whose job it was to discuss topics of sexuality, their own attitudes about sexuality and the patient's lack of readiness to discuss sexuality (Elliott et al., 2019; Herson et al., 1999).

Furthermore, existing resources have predominantly focused on the physical aspects of sexuality including erectile dysfunction and ejaculatory dysfunction (Anderson et al., 2007). However, recent work suggests that due to changes in the body resulting from SCI, men may adopt a new perspective on sexuality placing less emphasis on those physical factors and more importance on psychological and emotional components of sexuality including connection and intimacy with a partner and exploration of novel ways to experience sexuality beyond the traditional view of sex as a purely penetrative experience (Kathnelson, Kurtz Landy, Ditor, Tamim & Gage, 2020a). This study explored the lived experience of

sexuality for men after SCI and described the current state of tools and resources available to assist with sexual adjustment from the perspective of men living with SCI.

Materials and Methods

Data for this manuscript were collected as part of a larger study examining the lived sexual experiences for men after SCI. A paper has recently been published from that data which discussed the evolving meaning of sexuality for men after SCI (Kathnelson et al., 2020a). The present paper will report the health services information that was uncovered during that investigation.

Using Giorgi's descriptive, phenomenological approach (Patton, 2002), the lived experience of sexuality for men with SCI was explored. Phenomenological studies typically employ a small number of participants which allows for a deep and detailed exploration of the topic under investigation (Polit & Hungler, 1995). A minimum of three participants and a maximum of 10 has been recommended for this type of inquiry (Smith & Osborn, 2008; Creswell, 2007). Individuals were eligible to participate if they were male, between the ages of 18 and 50, living in Canada with a SCI of any level or classification and were able to communicate in English. Due to the novel, and therefore exploratory nature of this research, maximum variation was applied when establishing the inclusion criteria. Despite utilizing a convenience sampling approach, the purposefully broad inclusion criteria enabled a sample of participants that varied in terms of injury and demographic characteristics. This provided a broad view of the issues that exist regarding sexuality in this population. Patterns emerging from varied conditions are valuable in that they capture the core experiences of a phenomenon across contexts and identify factors of particular interest (Polit & Hungler, 1995).

Recruitment information was posted in relevant SCI groups on social media platforms, and any man who saw the post and was interested in the study was instructed to contact the researcher for more information. The first six men to respond were screened for eligibility, and upon determination that they met inclusion

criteria, they were invited to participate. All of the men who inquired about the study and who were eligible to participate agreed to be interviewed.

Rich and detailed descriptions were obtained by means of one-to-one interviews conducted with individuals who had first-hand lived experience with the phenomenon (Giorgi, 2009). Participants selected a pseudonym by which they would be referred to throughout the investigation, and each participant completed one in-depth confidential telephone interview (68 - 101 minutes; mean time 81 minutes). Interviews followed a standardized, open-ended approach combined with interview guide approach (see Appendix E for interview guide). The same key questions were asked in each interview ensuring conformity in the issues that were discussed with each participant while also allowing for exploration into new and relevant topics that were not anticipated, but which surfaced through discussion (Polit & Hungler, 1995).

Interview questions were developed based on previous literature and covered the six question types that have been suggested by Patton (2002): demographic, experience/behavior, knowledge, sensory, feeling/emotion and opinion/value (Polit & Hungler, 1995). Probing questions were used to further investigate certain topic areas. Interviews were audio recorded using a Sony ICD-PX370 digital voice recorder and were transcribed verbatim. Field notes were documented during each interview.

Data were analyzed throughout data collection using Giorgi's method (Patton, 2002) and informed subsequent interviews (Liamputtong, 2009). After all interview transcripts were analyzed individually, a cross-case analysis was performed and interviews were analyzed together to shed light on the phenomenon across various contexts and relationships. Themes between transcripts were identified using Giorgi's method (Patton, 2002) and were supported by direct quotations from participants transcripts. Data were analyzed independently by two researchers and discussed until consensus regarding prominent themes was reached. A reflective journal was kept throughout the research process to make note of personal thoughts and opinions, to enhance transparency and maintain a record of research decisions generating an audit trail (Carpenter & Suto, 2008; Ortlipp, 2008).

A researcher's experience, beliefs and worldviews will ultimately influence the way a study is conducted and presented (Giorgi, 2009). The primary researcher who conducted the interviews, performed data analysis and structured this manuscript is an able-bodied female with more than 10 years of spinal cord injury research experience. She has performed numerous qualitative studies, but operates from a post-positivist perspective and applies a quantitative lens to qualitative work (Giorgi, 2009). A descriptive phenomenological approach was employed to describe the experience of others with lived experience regarding the phenomenon, and personal interpretation by the researcher was avoided (Cohen & Omery, 1994). To ensure the results presented stayed close to the data, direct quotations from participant transcripts were used to support statements made by the author.

Ethical approval was obtained from the York University Research Ethics Board and the Brock University Research Ethics Board.

Results

Participants

Six men between the ages of 24 and 49 who were living in Canada with complete or incomplete SCI (C4-T12) participated in this study. Participants' time since injury ranged from seven months to 29 years (mean ~14 years). All of the men identified as being heterosexual. Tables 1 and 2 provide information on demographic and injury characteristics, and sexuality and relationships, respectively.

Table 3 - Demographic and Injury Characteristics

Participant	Age	Injury level / classification	Time post-injury
"Joe"	24	C7 incomplete	6 years
"Elliott"	32	C4 incomplete	15 years
"Will"	45	T9 complete	28 years
"Steve"	49	C4/C5 incomplete	29 years
"Paul"	49	T12 incomplete	7 years

“Peter”	47	T6 complete	7 months

Table 4 - Sexuality and Relationship Characteristics

Participant	**Sexual orientation**	**Relationship status (current)**	**Relationship status (at injury)**	**Sexual activities (post-injury)**	**Sexual activities (pre-injury)**
“Joe”	Heterosexual	In a relationship	In a relationship	Yes	No
“Elliott”	Heterosexual	Married	In a relationship	Yes	Yes
“Will”	Heterosexual	Married	Single	Yes	Yes
“Steve”	Heterosexual	Married	In a relationship	Yes	Yes
“Paul”	Heterosexual	Divorced	Married	Yes	Yes
“Peter”	Heterosexual	Married	Married	No	Yes

Unmet Need for Sexual Health Information

All of the participants in this study said the number of resources available and/or provided to them during rehabilitation was inadequate, and that the content of available resources was also inadequate. Generally, the participants explained that sexuality was briefly touched on in rehabilitation, but that it was not a priority, stating there was no real emphasis on the topic and that discussions about sex were “*in passing”* (Joe). They described a lack of time to discuss sexuality with their healthcare providers, as well as a greater focus on other areas of healthcare in rehabilitation programs. *“I think when you’re in a rehabilitation setting, they tend to have a lot of focus on like the importance of physiotherapy, the importance of occupational therapy and why you do that. They try to enlighten you on your bladder issues after your spinal cord injury, your bowel issues, the importance of your skin integrity, pressure sores, and they cover a lot of other really important things. But for some reason a lot of them have these really long check lists, but they always leave off the sexual health aspect after spinal cord injury”* (Elliott).

Participants explained that because everyone experiences sexuality differently, it could be

difficult to provide relevant information which may contribute to the lack of attention to sexuality in rehabilitation programs. Additionally, participants recognized the sensitive nature of the topic and stated sex was not something people wanted to talk about. As a result, it was a difficult conversation for the men to start and they tended to rely on their healthcare providers to initiate the discussion. Unfortunately, this conversation did not always transpire. Joe said: *"[in rehabilitation] sex is just briefly mentioned. Like they ask if you have any questions and then it's done, you never talk about it anymore. There's no actual emphasis on sex and sexual function. It was very much in passing. You could kind of tell they didn't really want to talk about it or that they were just checking it off a list. Just like, 'okay I mentioned sexuality, let's move on to the next thing.' It was very brief. I think because their focus is more on the physical rehabilitation and they are trying to get people moved through there."*

In some situations where information was provided, the participants said that resources did more harm than good by making sex after SCI seem unappealing. One example of this was a VHS tape that portrayed a couple pausing mid-sexual act to allow the man with SCI to empty his bladder with the help of his partner before continuing. Elliott relayed his experience: *"They gave me a really strange VHS tape and it was bizarre (laughs) and probably did more harm than good. It was a tape, specifically about sex after spinal cord injury. And it was from the 80s. And it was ridiculous. Like it had a bunch of different couples engaging in a variety of different sexual acts. Obviously, it exposed me to the reality of it, but at the same time I was like, 'I don't like this and I don't like [it] if that's what the rest of my life is going to look like with spinal cord injury and sexuality."* Information provided in rehabilitation and resources accessed on their own from the internet were occasionally unreliable and inaccurate compared to what they actually experienced. Joe shared: *"Google provided me with some information, but not all that information is correct."* The reported absence of resources was not a result of the men's disinterest in sexuality or sexual education post-injury. *"It was a conversation I was thinking about and the conversation that I wanted to have, but they didn't really answer a lot of the questions that I was looking for. So*

okay, yes you can have sex, but that's where it ended" (Elliott).

Healthcare Provider's Knowledge and Comfort Discussing Sexuality

Participants revealed their healthcare providers were knowledgeable about medications that could assist with sexual activities post-injury, including possible complications and interactions, and said their healthcare providers were somewhat knowledgeable on the physiology and lacked a crucial component for understanding the topic as they did not have any personal knowledge of what it means to experience sexuality after SCI. *"It's hard to say if doctors are knowledgeable about sex after spinal cord injury because not a ton of those conversations have ever taken place. Umm, yes, I mean they're knowledgeable about sexuality in general, but in how it's going to work as a function of life after the injury, meh"* said Paul. As a result, several participants felt they knew more about the topic than their healthcare providers: *"I know from a personal perspective, I probably know more about this [sex after SCI] through all the research that I've done than my spinal cord injury doctor does. So, like he knows a certain amount of things, but I don't think he knows more than I do"* Elliott explained.

Participants said the information they received from healthcare providers about sexuality was too clinical and too technical. According to the men, healthcare providers failed to address aspects of sexuality beyond the traditional assumption of sex as a physical penetrative act, and focused solely on physical components of sexuality that may be more relevant to individuals who are able-bodied. Participants wished to be educated on new ways to approach sexuality that were 'outside the box' and that may be better suited to those with SCI. Elliott said: *"It's just like, 'we're not going to help you think outside the box and realize you can use other devices, or you don't just have to get to penetration.'"*

Additionally, participants explained that healthcare providers were often uncomfortable discussing sexuality, though this was an assumption for some based on the premise that no

conversations about sex had ever taken place. Lastly, participants said that their healthcare providers did not understand the importance of talking about, and learning about, sexuality after SCI. "*...I think a lot of them [healthcare providers] don't really understand the importance of it [sex], and maybe they're not comfortable bringing it up"* explained Elliott.

Importance of Receiving Sexual Health Information

Participants clarified that it was important to include the topic of sexual health in rehabilitation programs and to achieve satisfaction in their sexual lives as sexuality was linked to their physical health, mental health, and to their overall well-being. They said that by improving their sexual experiences and sexual satisfaction post-injury, other health issues, both mental and physical, would also improve which would lead to improvements in their overall QOL. *"It's [sex] not only linked to your physical health. Like this can have a direct impact on your psychological health and your mental health and it could be triggering a lot of other things [physical and mental health issues]. My thoughts about myself, and just life in general is not always the greatest, but they probably would be if my sexuality was a little bit more positive"* (Elliott).

Participants revealed that sexuality was not prioritized in rehabilitation, however, receiving information about sexuality and having a fulfilling sexual life post-injury were identified as being important. For some, being adequately informed about sexuality-related topics could have resulted in different outcomes for their lives. One participant disclosed that he 'wasted' time during what should have been his peak sexual activity years due to a lack of sexual education and believing that he could not have sex as a result of his SCI. This participant believed his life may have been different, and that he could be in a different place than he is now if someone had told him that participating in sexual activities and experiencing a satisfying sexual life were still possible post-injury. *"I wasted 6-7 years of perfect university time and like experimenting which is what a lot of people do in university. But I skipped over 4 years of my undergrad thinking that*

a lot of that stuff was not possible. So, I think if somebody told me earlier on that I could still have sex and brought all of this to my attention, I would probably be in a very different position today than I am" (Elliott).

Recommendations for Sexual Health Information

Participants made recommendations for the most appropriate and effective delivery of sexual health education information post-injury. Participants said it could be overwhelming to search for this information on their own and suggested it would be most helpful if there was one designated place they could go to find all relevant information, whether that be a designated sex therapist or a 'sexpert,' an online email address they could send their questions to and receive accurate responses, or an information hub containing links to all of the existing sexual health resources. "*It'd be cool to see them have someone there that's actually trained in sexuality. Someone with actual resources. We need a hub of information"* said Joe.

Participants were somewhat open to receiving information from a variety of healthcare providers, however, some did convey that while their doctors may be helpful for explaining the physical aspects of sexuality, they would not be the best person to have this conversation with. Participants said it was difficult to discuss sexuality with their doctors with whom they had existing relationships for fear of being judged. They said their doctors held a position of power which made it challenging to be vulnerable with this very personal issue, and said this exchange seemed too formal. Generally, participants preferred to receive this information from a peer, someone of a similar age and injury who could relate to their lived personal feelings and experiences. *"The biggest thing is for the person who's giving you information to say 'oh yeah, the first year of my injury I had these feelings, and often people feel this,' rather than saying, you know, 'there is this medication and this medication' with like a much more kind of textbook-type description. Like more of a personal kind of experience is better"* Joe shared.

Participants identified open communication in a no judgement zone as being important when discussing sex, and said that sex should be incorporated into rehabilitation programs by covering the topic the same way they cover other health issues such as bladder management or skin integrity. Elliott said: *"I think a really easy way to integrate it is to have it as an option. And then okay, you cover bladder one week or bring that up one week, the next week you cover sexuality. Because it is really not that different when you think about it, since it's all part of your health care."* Having someone reach out early on after injury and open the door for conversations about sex was identified as being important, and a small gesture that could make a big difference would be to just *'bring it up'* and get the conversation about sex going. Joe suggested: *"I think there should be a person that would reach out early on, like a sex specialist*."

Participants also discussed the optimal timing to receive this information. Majority wished to receive information about sexuality immediately after injury, and then continue to receive it when they are back in the community and ready to use it. Peter shared the following: *"I would probably want to know about it as soon as possible. I would like awareness of information. Whether you actually execute it or not is different, but I would like to know the facts, all that, ahead of time. And then I can learn from it and be better educated when that time comes."* Will had a similar perspective: *"Do it sooner rather than later because that's a problem that we had. There were no resources that we were given on how to handle this stuff [sexuality]. If I could make one change in how that's all done, is make sure that that is a topic that's covered as early as possible."* Conversely, some men wanted to wait at least a year before receiving this information, explaining that for the first year they had other priorities and/or did not feel like a sexual person. Steve said: *"Oh I would at least give it a year because you're so busy trying to You're trying to do rehab, that sort of stuff."* Considering these two perspectives, information should be made available and offered to men soon after injury which may provide answers to the questions they have early on about sexuality and also inform them that sex is still an option. Knowing this information is available, the men can choose to access it when they are ready to do

so.

Discussion

This study contributed to further understanding the experience of sexuality for men after SCI and revealed that healthcare providers, rehabilitation programs and available resources are, in general, not meeting the needs of men with SCI. Current literature has reported difficulties integrating the topic of sexual health into rehabilitation programs for those with disabilities (Pieters et al., 2018). While many healthcare providers do consider sexuality an important issue to approach during rehabilitation, a study of 244 healthcare providers found that only 12% felt sufficiently trained to address the topic (Gianotten et al., 2006). Healthcare providers revealed that sexual health was rarely incorporated in their training curriculum and felt that it was not their professional responsibility to handle (Gianotten et al.2006). This may account for comments made by the men in the current investigation regarding the availability of sexual health resources and the knowledge and comfort level of their healthcare providers to cover the topic.

Men continue to have concerns about sexuality years after their SCI (Consortium for Spinal Cord Medicine, 2010) and agree that continued access to sexual supports after leaving rehabilitation is important, yet there is little consensus regarding the delivery of this information (Aikman et al., 2018). Healthcare providers working in sexual rehabilitation have identified the need for a standardized and multidisciplinary approach which incorporates expertise from various disciplines to effectively address the complexity of sexual health (Elliott et al., 2017; Pieters et al., 2018). Researchers have launched a project to improve standards of SCI rehabilitation in Canada by 2020, including sexual health. The project aims to encourage a liberal environment regarding sexuality after SCI and to pinpoint sexual health needs through identification, development and implementation of key indicators related to sexual health after SCI (Elliott et al., 2019). Initiatives such as these are vital for better meeting the needs of this population regarding their sexual health.

The top preference of the participants in this study for receiving information about sexual health was an informal, non-technical, non-clinical approach from one designated 'sexpert.' That being said, open communication in an uncritical environment with someone who is approachable and receptive was important for improving the quality of the interaction between the patient and the healthcare provider. In a study which looked at improving sexual rehabilitation services from the perspective of the patient, McAlonan (1996) found that interpersonal skills and character traits of the healthcare provider including an open and friendly personality, and comfort and confidence to both talk and listen during discussions about sexuality were more important than who provided the information and what their role as a healthcare provider was (McAlonan, 1996).

Participants conveyed that sexual health information would be most beneficial if it took into account the changed body after SCI. They suggested that resources should help them *'think outside the box'* and suggest new ways to explore and experience sexuality. Resources should consider ways of experiencing intimate connection beyond the traditional view of sexuality which has been focused on erection, penetration and ejaculation (Sunilkumar et al., 2015). Conventional sexual health information should be provided, but it is important that researchers, clinicians and healthcare providers are open to expanding their views of sex and sexuality when working with this population by considering and discussing alternate ways in which individuals living with SCI may be able to explore and experience sexuality. Finding a balance between open conversation and respecting the comfort level of both the patient and healthcare provider should be explored. Healthcare providers discussing sexual activities post-injury should be aware of their own biases and should be prepared to suspend any judgements to facilitate safe and productive discussions about sex (Smith & Osborn, 2008).

It is important that researchers and clinicians consider the needs of the individuals they aim to assist by involving them in the development and evaluation of programs and treatments, maximizing the potential for benefits to be experienced. Future work should ensure that from the perspective of the patient, sexual health programs are being developed and delivered in an effective and suitable manner.

Strengths and Limitations

This qualitative approach allowed the men's voices regarding their own sexuality to emerge. The sample reflected a spectrum of heterosexual men's experiences regarding their sexuality across various ages, time points since injury, injury levels and injury classifications.

The average time since injury for these participants was approximately 14 years. It is possible that rehabilitation practices have been updated or improved since some of these men were in rehabilitation programs, though information provided by the most recently injured participant (seven months post-injury) was consistent with the others. All of the participants in this study were male and identified as heterosexual. The results from this study may not elucidate the opinions of individuals outside these parameters. The goal of phenomenological work is to uncover the personal lived experiences of individuals who have first-hand knowledge of the topic under investigation and is not meant to be representative of a population (Polit & Hungler, 1995). While the small sample size was appropriate for this type of deep and exploratory study, additional research using a larger number of participants may be beneficial for application to a wider population. Data reported here are a subset of information obtained from the interview guide that are relevant to sexual education and sexual rehabilitation post-injury. Themes identified from the transcripts in their entirety are intertwined, and the evolving meaning of social constructs related to sexuality for men after SCI should be considered when developing sexual rehabilitation frameworks. Data derived from other sections of the interview guide can be found in Kathnelson and colleagues (2020a) and may be reviewed to obtain a deeper understanding of the basis for recommendations made in this paper (Kathnelson et al., 2020a).

Conclusions

Normalization of the topic of sexuality after SCI is important in facilitating conversations about sex for both patients and healthcare providers (Eisenberg, Andreski & Mona, 2015), and sexual health should be

a standard component of rehabilitation that is offered to all patients, not just those who are assertive enough to ask for it (Pieters et al., 2018). Healthcare providers should be aware of the resources available in their communities (Consortium for Spinal Cord Medicine, 2010) and sexual health should be fully integrated into rehabilitation programs and primary care facilities for individuals living with SCI (Aikman et al., 2018). Participants felt they should have access to a healthcare provider trained in sexuality who would have the skills and resources to address their concerns. Participants also noted that a good first step for moving forward with sexual education post-injury would be for healthcare providers to '*just bring up'* the topic and initiate a conversation about sex.

Information from this study may help inform the development and delivery of effective sexual education for men after SCI and guide future rehabilitation initiatives to improve QOL and overall life satisfaction for these individuals.

CHAPTER 4: UTILIZING THE DELPHI METHOD TO ASSESS ISSUES OF SEXUALITY FOR MEN LIVING WITH SPINAL CORD INJURY

The work in this chapter reflects the work of the candidate with minimal contribution, suggestion and editing from the supervisor and the committee. A copy of the published version is included in the appendices.

Abstract

This study investigated the physical and psychological issues of sexuality for men after spinal cord injury and identified areas of top concern. Using the Delphi Method, a panel of expert judges (twenty men with spinal cord injury [SCI], C3-T12, age 26-59) completed a series of three questionnaires in an attempt to reach a consensus on previously identified issues. It was agreed that SCI affects physical and psychosocial aspects of sexuality and that sexual support is limited for exploring sexuality post-SCI. Additionally, insight into the social constructs of masculinity, gender roles, body image and disability and their influence on the sexual experiences of this population is provided. Enhancing patient, healthcare provider and societal awareness of sexuality for men after spinal cord injury should be an immediate area of focus to improve sexual and overall quality of life for this population.

Introduction

In a rehabilitation setting, it is estimated that 100% of adults with SCI experience sexual dysfunction and issues with sexual intimacy and sexual relationships (Gianotten et al., 2006). While we are widely exposed to sexuality in society through advertising and social media, exposing and discussing one's personal sexual life remains difficult (Reel & Davidson, 2018). Furthermore, while society has shifted towards a greater acceptance of diversity in sexuality this vision may not extend to sexuality and disability where common myths still contribute to the perception of individuals with disabilities as asexual (Reel & Davidson, 2018). Though sexual health has been validated as a top priority for

individuals with SCI, resistance in addressing the topic has led to a disconnect between available resources and need (Elliott et al., 2019).

Spinal cord injury not only affects physical aspects of sexuality, but also social and psychological factors as well (Aikman et al., 2018; Kathnelson et al., 2020a). Beyond affecting intimacy, relationships and sexual functioning, the effects of SCI on sexuality may extend to one's identity, self-worth (Stein et al., 2018) and self-esteem (Elliott et al., 2019), and can lead to social isolation, depression and often contributes to a lower quality of life (QOL) (Siösteen et al., 1990). Learning to adapt to the physical, psychological and psychosocial dimensions of sexuality after SCI is therefore important to living a fulfilling sexual life post-injury (Elliott et al., 2019).

In a recent study by Kathnelson and colleagues (Kathnelson et al., 2020a) in-depth interviews were conducted with men living with SCI. The interviews revealed an extensive list of concerns that men with SCI experience with regards to sexuality post-injury. Topics included physical aspects of sexuality, but focused on psychological and emotional concerns influencing the participants' experience of sexuality post-injury. Issues regarding the availability of sexual health information, tools and resources, as well as the delivery of this information were also identified.

The current study aimed to 1) further explore previously identified issues regarding sexuality among men with spinal cord injury (Kathnelson et al., 2020a) using the Delphi Method; and 2) identify areas of top concern regarding sexuality for men with SCI with a focus on psychosocial factors.

Materials and Methods

The Delphi Method is a consensus tool which systematically and interactively leverages and documents the opinions of an expert panel of judges to reach an agreement on relevant topics (Shah & Kalaian, 2009). This is accomplished through a series of questionnaires with controlled feedback (Sklumoski et al.,

2007) and is appropriate for use in areas of uncertainty or where knowledge is incomplete (Powell, 2002; Sklumoski et al., 2007), including, as with the current study, male sexuality after SCI. The anonymity of the Delphi Method facilitates information exchange on personal and sensitive topics while avoiding the negative dynamics associated with group discussion including status, overbearing personalities and pressures to conform to group ideals (Thangaratinam & Redman, 2005).

Participants and Recruitment

When utilizing the Delphi method, adherence to a specific set of inclusion criteria is important when selecting the panel of experts. Additionally, a panelist must possess knowledge of, and have practical experience with the topic; a panelist must have the ability, willingness and available time required to participate in the Delphi surveys; and a panelist must possess effective communication skills (Sklumoski et al., 2007).

Earlier research has confirmed that an effective panel size for use with the Delphi Method is generally comprised of less than 50 individuals (Witkin & Altschuld, 1995), and that most studies using this technique engage a panel of 15-20 individuals (Ludwig, 1997). Based on these criteria, a panel of 20 experts was recruited. Men with varying levels and classifications of SCI who were over the age of 18, living in Canada and were able to communicate in English were recruited to form our expert panel. Panel members were recruited by means of recruitment posters in the Power Cord Rehabilitation Centre at Brock University, via posts on relevant social media platforms, by distribution of study information to men with SCI through Spinal Cord Injury Ontario and by word of mouth.

Participants provided online consent prior to participating in the study. The first page of the online survey contained a display logic that took the participant to question one of the survey if he chose the response providing his consent to participate. In the event that a participant selected the response that did not

provide his consent to participate, he was taken to a screen thanking him for his time before being prompted to exit the survey. This process was repeated at the beginning of the second and third rounds of the survey to ensure ongoing consent. All participants provided consent at all time points. Upon completion of the surveys, participants received a $10 gift card as a thank you for their time. Ethics approval was obtained from the York University Research Ethics Board and from the Brock University Research Board.

Data Collection

An iterative process involving three rounds of questionnaires was employed to reach a consensus on relevant topics (Delbeq, Van de Ven & Gustafson, 1975). Most Delphi studies use two or three rounds as an increased number of rounds will lead to participant fatigue and ultimately, attrition (Keeney, Hasson & McKenna, 2001; Thangaratinam & Redman, 2005). In round one, panel members received a structured questionnaire based on the items derived from interviews in Kathenlson and colleagues (2020a) (refer to Appendix E for interview guide). Panelists were asked to review the items and indicate their level of agreement on a seven-point Likert Scale that ranged from strongly agree to strongly disagree. Panelists were also asked to rate and rank several items in order of importance. Additionally, three open-ended questions were included to provide the current panelists with opportunities to add their opinions regarding relevant topics that might not have been identified in the earlier research, to clarify or expand on responses from closed-answer questions and to explain any potential issues with the questions. In round two, panel members received a modified questionnaire that had been based on feedback from the previous round, as well as information on the items and their ratings from round one. Information about the position of their scores in relation to the scores of others from round one was provided anonymously and was presented throughout the survey with each question. Panel members were given the opportunity to modify their scores to facilitate movement towards reaching a consensus (Powell, 2002). In this round, participants were given four opportunities to provide responses to open-ended questions. In the third and

final round, the panelists received a list of the remaining items that had not reached a consensus and their ratings as well as a modified questionnaire based on open-ended responses from the previous round. This was the final opportunity for panel members to revise their judgements. If a panel member chose not to change his score and remain outside the group majority, he was given the opportunity to specify his reason(s) for remaining outside the consensus. After three rounds of consultation by our expert panel, the agreed upon items reflected the final list of relevant issues and non-issues regarding sexuality for men after SCI. Surveys were hosted online on Qualtrics^{XM}, an online platform used to obtain feedback from participants via automated and integrated workflows.

Data Analysis

Consensus was defined as ≥70% of responses in either the positive end (strongly agree, agree or somewhat agree) or the negative end (strongly disagree, disagree or somewhat disagree) (De Villiers, De Villiers & Kent, 2005; Meshkat et al., 2014; Sumsion, 1998). Data were analyzed using measures of central tendency (mean and mode) to demonstrate total group ratings. These tests revealed the level of consensus that was achieved and determined whether convergence, or a move towards central tendency, and thereby an increase in the strength of the agreement was accomplished throughout the three rounds (Hasson et al., 2000; Holey, Feeley, Dixon & Whittaker, 2007; Hsu & Sanford, 2007). Qualitative data from open-ended questions were analyzed using conventional content analysis (Sklumoski et al, 2007). Data were read repeatedly by the primary investigator and central thoughts and concepts were noted. Codes representing these key ideas were derived from the data and were organized into categories that described the perspectives of the participants (Hsieh, 2005).

Results

Participants

Twenty men between the ages of 26 and 59 (mean age 43.6 years; 10% age 25-29, 10% age 30-34, 5% age 35-39, 30% age 40-44, 15% age 45-49, 20% age 50-54, 10% age 55-60) living in Canada with complete (55%) or incomplete (45%) SCI (C3 - T12) were recruited to form the expert panel. The average time since injury for the panelists was 16.75 years, and ranged from <1 year to 33 years. All of the men identified as heterosexual. Eighteen of the men had participated in sexual activities and had had sexual intercourse prior to their respective injuries. Seventeen men had participated in sexual activities post-injury and sixteen had had sexual intercourse post-injury. Relationship statuses at the time of the study were single (20%), separated (5%), divorced (5%), in a relationship (20%), common law (20%) and married (30%). Table 5 outlines demographic and injury characteristics, and Table 6 outlines sexuality and relationship characteristics.

Table 5: Demographic and Injury Characteristics

Age group	Injury level / classification	Time post-injury
40 - 44 years	C7 incomplete	21 - 25 years
35 - 39 years	T6 complete	31 - 35 years
45 - 49 years	T12 incomplete	16 - 20 years
25 - 29 years	T4 complete	6 - 10 years
40 - 44 years	T12 incomplete	21 - 25 years
25 - 29 years	C7 incomplete	6 - 10 years
40 - 44 years	C5 complete	11 - 15 years
45 - 49 years	T4-T5 complete	< 1 year
50 - 54 years	C3 incomplete	11 - 15 years
40 - 44 years	T6 complete	21 - 25 years
55 - 60 years	T3 complete	31 - 35 years
50 - 54 years	T11-T12 incomplete	1 - 5 years
50 - 54 years	C7 incomplete	31 - 35 years
40 - 44 years	T12 complete	1 - 5 years
55 - 60 years	T10 complete	26 - 30 years
45 - 49 years	C3-C4 incomplete	16 - 20 years
40 - 44 years	C5 complete	1 - 5 years
30 - 34 years	C6-C7 incomplete	11 - 15 years
30 - 34 years	T2 complete	1 - 5 years

50 - 54 years	T7-T8 complete	26 - 30 years

Table 6: Sexuality and Relationship Characteristics

Sexual Orientation	Relationship Status		Sexual Activity		Sexual Intercourse	
	Pre-injury	Post-injury	Pre-injury	Post-injury	Pre-injury	Post-injury
Heterosexual	Single	Common-law	Yes	Yes	Yes	Yes
Heterosexual	Single	Common-law	No	Yes	No	Yes
Heterosexual	Married	In a relationship	Yes	Yes	Yes	Yes
Heterosexual	Single	Single	Yes	Yes	Yes	Yes
Heterosexual	Single	In a relationship	Yes	Yes	Yes	Yes
Heterosexual	In a relationship	In a relationship	Yes	Yes	Yes	Yes
Heterosexual	In a relationship	Single	Yes	Yes	Yes	Yes
Heterosexual	Unknown	Married	Yes	No	Yes	No
Heterosexual	Unknown	Divorced	Yes	Yes	Yes	Yes
Heterosexual	Single	Common-law	Yes	Yes	Yes	Yes
Heterosexual	Married	Married	Yes	Yes	Yes	Yes
Heterosexual	Married	Married	Yes	No	Yes	No
Heterosexual	In a relationship	Married	Yes	Yes	Yes	Yes
Heterosexual	Married	Married	Yes	Yes	Yes	Yes
Heterosexual	Single	In a relationship	Yes	Yes	Yes	Yes
Heterosexual	Single	Separated	Yes	Yes	Yes	Yes
Heterosexual	Married	Married	Yes	No	Yes	No
Heterosexual	In a relationship	Common-law	No	Yes	No	Yes
Heterosexual	Single	Single	Yes	No	Yes	No
Heterosexual	In a relationship	Single	Yes	Yes	Yes	Yes

Round One

Twenty surveys were distributed in the first round with a 100% response rate. In this round, 28 of 60 items reached a consensus (46.7%). Of those 28 items, 15 (53.6%) reached a level of moderate agreement with ≥70% of responses in either the positive end (strongly agree, agree or somewhat agree) or the negative end (strongly disagree, disagree or somewhat disagree). Thirteen items (46.4%) reached a level of strong agreement with ≥70% of responses in either the high positive end (strongly agree or agree) or high negative end (strongly disagree or disagree) (De Villiers et al., 2005; Meshkat et al., 2014; Sumsion, 1998). Table 7 lists the items that reached a consensus in round one.

Table 7: Items Reaching a Consensus in Round One

Question	**Level of Agreement**	**Percent Agreement**
I believe that sex is both a physical and a psychological/ emotional experience	Strong agreement	95% high positive 100% positive end
I believe that sexuality is about more than just sex	Strong agreement	95% high positive 95% positive end
I think that sex involves more than just penetration	Strong agreement	95% high positive 100% positive end
Emotional closeness with my partner during sex has become more important since my SCI	Moderate agreement	45% high positive 70% positive end
I think the sexual experience is more enjoyable when there is an emotional/ psychological connection with my partner rather than just a physical connection	Strong agreement	95% high positive
Finding new ways to experience sexual satisfaction has become more important since my SCI	Moderate agreement	80% positive end
Open and honest communication with my partner about sex has become more important since my SCI	Strong agreement	70% high positive 80% positive end
I focus more on my partner's sexual satisfaction since my SCI	Strong agreement	70% high positive

		75% positive end
I get sexual satisfaction through my partner's sexual satisfaction	Strong agreement	90% high positive
The way I view my own masculinity has changed since my SCI	Moderate agreement	75% positive end
People only see my SCI when they first look at me	Moderate agreement	75% positive end
Because of my SCI, I am concerned for my physical safety when meeting new people	Strong disagreement	80% high negative 85% negative end
Changes in my body functions since my SCI have negatively affected my sexual life	Strong agreement	75% high positive 85% positive end
Changes in my sexual function since my SCI have added stress to my relationships	Moderate agreement	70% positive end
Decreased spontaneity in my sexual life due to SCI has had a negative effect on my sexual life	Moderate agreement	85% positive end
Positively adjusting to sexuality after SCI contributes to my personal growth	Moderate agreement	85% positive end
The longer I live with SCI, the more accepting I am of my injury	Moderate agreement	80% positive end
I wanted to receive education about sex after SCI	Strong agreement	70% high positive 80% positive end
I think it is important to receive education about sex after SCI	Strong agreement	80% high positive 90% positive end
I would find it helpful to receive information about the physical aspects of sexuality after SCI	Moderate agreement	75% positive end
I would find it helpful to receive information/ counselling about the psychological/emotional aspects of sexuality after SCI	Moderate agreement	70% positive end
Most of my knowledge about sex after SCI came from my health care providers	Strong disagreement	80% high negative 85% negative end
Most of my knowledge about sex after SCI came from my own research	Strong agreement	75% high positive 85% positive end

I think the information provided by health care professionals regarding sex after SCI is missing the personal experience that comes with actually living with a SCI	Moderate agreement	80% positive end
Increased sexual education after SCI could lead to increased sexual satisfaction	Moderate agreement	75% positive end
I am knowledgeable about alternate ways to achieve sexual satisfaction after SCI	Moderate agreement	70% positive end
I am affected by the misconceptions that society has about men who live with a SCI	Moderate agreement	75% positive end
Educating society about what it actually means to live with SCI could improve the dating experience	Moderate agreement	80% positive end

* Strong agreement/disagreement - ≥70% of responses strongly (dis)agree or (dis)agree
* Moderate agreement/disagreement - ≥70% of responses strongly (dis)agree, (dis)agree or somewhat (dis)agree
***** High positive/negative - strongly (dis)agree or (dis)agree
* Positive/negative end - strongly (dis)agree, (dis)agree or somewhat (dis)agree

Round Two

After distribution, participants were given one week to complete the second survey. Two follow-up e-mail reminders were sent to non-responders (three days after the initial survey distribution and a final reminder the day before the survey would close). Seventeen of 20 surveys were returned (85% response rate).

The 32 items that did not reach a consensus in round one were restructured based on feedback provided by participants (either altering the wording of the question or adding additional response choices), and were examined again in round two. Based on feedback provided in round one, five additional items were developed and incorporated in round two. A total of 37 items were included in round two, and 13 reached a consensus (35.1%). Twelve items (92.3%) reached a level of moderate agreement with ≥70% of responses in either the positive or negative end, and 1 item (7.7%) reached a level of strong agreement with ≥70% of responses in the high positive end. Table 8 lists the items that reached a consensus in round two.

Table 8: Items Reaching a Consensus in Round Two

Question	Level of Agreement	Percent Agreement
Sex has less to do with penetration since my SCI	Moderate agreement	43% high positive 79% positive end
I think that men with SCI are viewed as less masculine than men who are able-bodied	Moderate agreement	63% high positive 75% positive end
Dating is not worth the effort because I spend a lot of time explaining my injury and then the person is not interested anyway	Moderate agreement	62% high positive 70% positive end
If I was single, people may not want to date me because they don't want to end up being my caregiver	Moderate agreement	25% high positive 70% positive end
I am afraid of, or have been afraid of letting my partner down sexually	Moderate agreement	50% high positive 81% positive end
Changes in the way my body looks after SCI have at some point had a negative effect on my sexuality	Moderate agreement	44% high positive 75% positive end
I feel like something is missing from my life when I think about my sexual experiences now compared to before my SCI	Strong agreement	80% high positive 93% positive end
Sexual education was not a priority of my health care providers when I was in rehabilitation	Moderate agreement	63% high positive 88% positive end
I believe the information provided by health care professionals regarding sex after SCI is too clinical	Moderate agreement	39% high positive 77% positive end
I had my own misconceptions about living with a SCI that I had to overcome after my injury	Moderate agreement	56% high positive 86% positive end
At some point since my SCI, I have questioned what would make me attractive to a partner	Moderate agreement	59% high positive

		88% positive end
At some point since my injury I have compared my body to men who do not have a SCI	Moderate agreement	65% high positive 82% positive end
Decreased self-esteem negatively affects my sexuality	Moderate agreement	24% high positive 76% positive end

* Strong agreement/disagreement - ≥70% of responses strongly (dis)agree or (dis)agree
* Moderate agreement/disagreement - ≥70% of responses strongly (dis)agree, (dis)agree or somewhat (dis)agree
***** High positive/negative - strongly (dis)agree or (dis)agree
* Positive/negative end - strongly (dis)agree, (dis)agree or somewhat (dis)agree

Round Three

In round three, seventeen surveys were distributed and participants were again given one week to complete them. Follow-up reminders were sent to non-responders at the same intervals described in round two. Fifteen surveys were returned in the third and final round (response rate of 88%).

The 24 items that did not reach a consensus in round two were restructured based on feedback provided by participants and were asked again in round three. Of these 24 items, nine reached a consensus (37.5%). All nine items that reached a consensus were at a moderate level of agreement with ≥70% of responses in either the positive end or the negative end. No items in this round reached a level of strong agreement. Table 9 lists the items that reached a consensus in round three.

Table 9: Items Reaching a Consensus in Round Three

Question	**Level of Agreement**	**Percent Agreement**

Physical closeness (touching, cuddling, laying together) to my sexual partner has become more important than the act of penetration since my SCI	Moderate agreement	50% high positive 71% positive end
I avoid approaching new potential partners because I am afraid of being rejected	Moderate agreement	50% high positive 70% positive end
I have questioned my ability to attract a partner since my SCI	Moderate agreement	58% high positive 75% positive end
Changes to my level of independence after SCI have at some point negatively affected my self-esteem	Moderate agreement	60% high positive 73% positive end
Changes to my level of confidence after SCI have at some point, or my in the future negatively affect my self-esteem	Moderate agreement	47% high positive 75% positive end
My partner is afraid of hurting me during sex	Moderate disagreement	70% negative end
Having to monitor my body, or thinking about having to monitor my body during sexual activities may take away from the sexual experience	Moderate agreement	33% high positive 73% positive end
I try not to think about sexuality by refocusing my attention on other things	Moderate disagreement	53% high negative 73% negative end
My health care providers are knowledgeable about sex after SCI	Moderate disagreement	62% high negative 77% negative end

* Strong agreement/disagreement - ≥70% of responses strongly (dis)agree or (dis)agree
* Moderate agreement/disagreement - ≥70% of responses strongly (dis)agree, (dis)agree or somewhat (dis)agree
***** High positive/negative - strongly (dis)agree or (dis)agree
* Positive/negative end - strongly (dis)agree, (dis)agree or somewhat (dis)agree

After three rounds of surveys, a total of 15 out of 65 items (23.1%) did not achieve the minimum criteria to be considered a consensus. Table 10 lists the items that did not reach a consensus.

Table 10: Items that did not Reach a Consensus

Question	Result
If I put more focus on the emotional/ psychological connection with my partner, the sexual experience can be more satisfying than it was prior to my SCI	57% positive end
I am afraid that I will have to settle in terms of the partner I end up with	50% positive end
I have a fear of failure when in a sexual situation or when thinking about being in a sexual situation	47% positive end
Changes in my sexual function since my SCI have caused relationships to end	46% negative end
Due to my SCI, cleanliness of my body has, or may be, a concern during sexual activities	60% negative end
I am anxious about the side effects of medications that would help me have an erection (eg Viagra, Cialis etc)	47% positive end
Increased planning in my daily life due to SCI has had, or may have a negative effect on my sexual life	67% positive end
I am satisfied with the amount of information I received regarding sexuality after SCI	53% negative end
My health care providers are comfortable discussing sex after SCI with me	50% negative end
I am satisfied with the resources that are available regarding sex after SCI	60% negative end
I spend a lot of time educating my partner/ potential partners about sex after SCI	46% positive end
It is difficult to have a conversation about how sex works after SCI with partner/ potential partner	57% negative end
There are adequate resources available for my partner to access to learn about sex after SCI	64% negative end
I have a lower sexual drive now than I did prior to my injury	60% positive end
At some point since my injury I have compared my sexual performance to men who do not have a SCI	60% positive end

* Strong agreement/disagreement - ≥70% of responses strongly (dis)agree or (dis)agree
* Moderate agreement/disagreement - ≥70% of responses strongly (dis)agree, (dis)agree or somewhat (dis)agree
***** High positive/negative - strongly (dis)agree or (dis)agree
* Positive/negative end - strongly (dis)agree, (dis)agree or somewhat (dis)agree

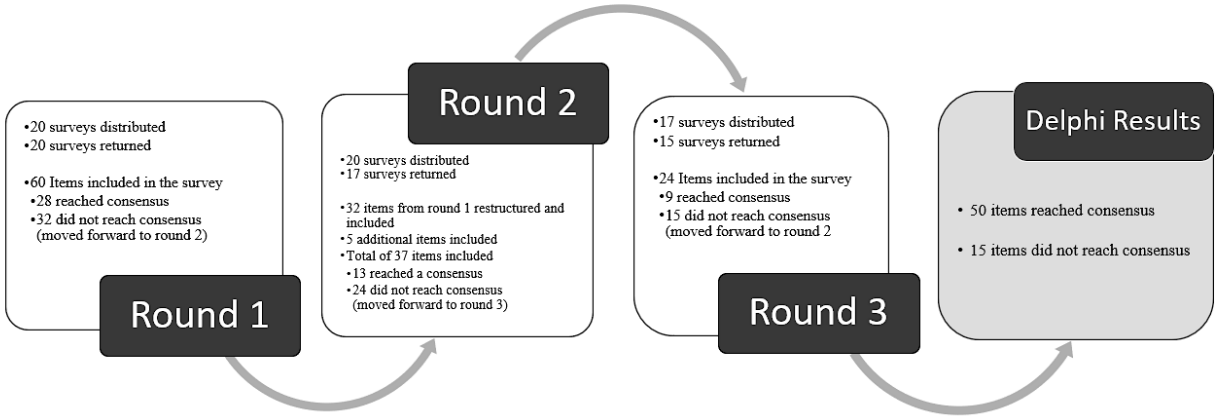

Figure 1: Delphi Process

Discussion

Sexuality

Sexuality may be defined and experienced in many ways (Hohmann, 1972). The men in this study strongly agreed that sex was both a physical and psychological experience that was more enjoyable when there was an emotional connection with their partner rather than just a physical connection. Previous research has also communicated this and has found that men with SCI experienced little meaning or gratification in sexual activities unless they were in a close relationship in which they cared for their partner (Hohmann, 1966; Hohmann, 1972).

The men in this study agreed that sex was about more than penetration and agreed that sex had less to do with penetration since their SCI. Consistent with earlier interviews (Tepper, 1999), other types of physical connection had become more important than the act of penetration. Physical closeness includes more than just genital touching (Hohmann, 1972), and sexual gratification may be experienced in many ways including touching, cuddling, kissing, laying together and oral sex, not just genital intercourse

(Kathnelson et al., 2020a; Tepper, 1999). One participant stated, "*I spend less time having penetrative sex now and more time with other types such as oral."* Furthermore, closeness may not mean only in a physical sense, but in an emotional sense as well. In a study by Leibowitz and Stanton (Leibowitz & Stanton, 2007), participants with SCI conceptualized sexuality in a way that stretched beyond purely physical sexual acts. The focus was less physical and included "*mental, spiritual, and emotional aspects of sexuality*" (Leibowitz & Stanton, 2007). Though some participants had reported sexuality as a predominantly physical experience prior to injury, none of the participants described sexuality in a purely physical, genital experience after injury. Emotional intimacy was rated as being more important than physical intimacy, and the level of sexual intimacy experienced was enhanced post-SCI.

The men did not reach an agreement on whether focusing on the psychological and emotional connection with their partner could make the sexual experience more satisfying than it was prior to injury. One participant shared, *"reduced sensation negatively affects my sexual satisfaction beyond what any compensatory methods can improve.*" Though a consensus was not achieved, the highest number of responses did fall in the positive end, and 57% of men reported that by focusing on psychological and emotional connections, their sexual lives could be more satisfying than they were prior to injury.

The men reported that exploring new ways to experience sexuality was more important post-injury. Previous literature has stated that sexual exploration is important after SCI as men may experience decreased genital sensation and may be unaware of other areas of the body capable of producing pleasurable sensations (Tepper, 1999). Through sexual exploration, new erogenous zones may be identified (Hohmann, 1966). The men generally agreed that they were knowledgeable about alternative ways to achieve sexual satisfaction post-injury, and also agreed that open and honest communication about sex with their partners had become more important post-injury.

The men stated that they tended to focus more on their partners' sexual satisfaction now than they did prior to injury, and agreed that they experienced satisfaction through their partners' sexual satisfaction, which was consistent with the preliminary interviews (Kathnelson et al., 2020a). Previous literature has also found that men with SCI experience satisfaction through the pleasure their partner experiences upon reaching orgasm. Hohmann (1972) describes *"empathetic gratification"* in which an individual with SCI may experience psychological and physical responses associated with build-up and orgasm at the same time the partner reaches orgasm. This phenomenon was referred to as a "*para-orgasm.*" Men with SCI have also reported not being as concerned with their own sexual pleasure (Tepper, 1999), and one participant in the current investigation wrote, *"Not being able to orgasm myself is very low on my priority list, but not being able to give in every way is tough mentally to deal with as a man."*

The men agreed that they are, or have been, afraid of letting their partner down sexually since their injury, but did not agree that they have a fear of failure when in a sexual situation. One participant explained, "*confidence overcomes and meds [medications] help."* Other men shared that being in a *"solid relationship"* also helps.

Though no consensus was reached, many men (60%) reported comparing their sexual performance to men who do not have a SCI. In an additional comment, one man wrote, *"I can't help but compare my sexual functioning to other neuro-typical men my age, and sometimes this makes me feel less virile."* In contrast, one man who did not respond with the group said *"I don't care what other men do. It's like comparing myself to porn, unrealistic and we are whom we are."* Comparing sexual experiences and sexual performance pre and post-injury can have potentially detrimental effects. Perceptions of pre-injury sexual performance are subject to a memory bias and may be skewed as men tend to glorify their previous sexual experiences (Tepper, 1999). The men strongly agreed that something was missing from their lives when they thought about their current sexual experiences compared to those before SCI, and agreed that they try not to think about this by refocusing their attention on other things.

No consensus was reached regarding the topic of sexual drive, however, the highest number of responses (60%) did fall in the positive end suggesting the men had a lower sexual drive post-injury compared to before SCI. Men who did not respond with the group provided the rationale that *"my sex drive is just as high, I enjoy sex," "my sex drive hasn't changed, just my ability,"* and *"the chair [wheelchair] has nothing to do with my sex drive."* In previous literature, psychosexual desire has been reported to remain similar after SCI, and patients with SCI often maintain the same sexual interests they had prior to injury (Talbot, 1971; Willmuth, 1987). Using the Sexual Functioning Index, Romeo and colleagues (1993) found no difference in sexual drive or sexual fantasies between men with SCI and men who did not have a SCI.

Prior research has found that the majority of individuals strongly feel that their SCI has interfered with their sexual activities (Elliot et al., 2019). The men in the current investigation agreed that changes in their bodily functions and appearance as a result of SCI had negatively affected their sexual lives, and that changes to their sexual function had added stress to their relationships. However, the highest number of responses (46%) did not agree that changes to their sexual function had caused relationships to end. Conversely, one participant whose response remained against the group shared, "*I've had two relationships end solely because of my injury."* This comment may be more in line with previous research which has found an initial period after SCI where there is a significantly higher risk of divorce and separation (DeVivo & Fine, 1985; Kretuer, 2000) due to difficulties adapting to altered physical function and challenges maintaining the relationship (Kreuter, Sullivan, Dahllöf & Siösteen, 1998).

In general, the men reported that they did not believe that their partners were afraid of hurting them during sex, but having to monitor their body for potential issues during sexual activities was thought to take away from the sexual experience. Also taking away from the sexual experience was decreased spontaneity in their sexual life as a result of the injury. One participant explained, "*being unable to have*

intercourse is a hard thing to deal with as a man… Not being able to have a spontaneous erection has been very difficult emotionally." Accordingly, these concerns were reported to have a negative impact on the sexual life of these men. While decreased spontaneity in their sexual life was problematic, the men did not agree that increased planning in their daily life due to SCI had a negative effect on their sexual life. Due to physical limitations that made performing personal hygiene activities increasingly difficult it had been previously noted that, cleanliness of the body during sexual activities could be a concern (Kathnelson et al., 2020a). The men in the current study did not agree that cleanliness of their body was a concern during sexual activities, stating that *"cleanliness is always important, regardless of SCI or not,"* but one participant noted that *"bowel and bladder functions have to be a concern [after SCI]."* The men did not agree that they felt anxious about the side effects of medications that would help them have an erection.

In this study, participants in higher age ranges (50 to 60 years of age) continued to identify sexuality as an important aspect of their lives. This is consistent with Lombardi and colleagues (Lombardi, Macchiarella, Cecconi, Aito & Del Popolo, 2008) who found that sexuality continued to be important to men over the age of 50 and men who had been injured for over 20 years. This has also been recorded in numerous other sources (Burns et al., 2009; Consortium for Spinal Cord Medicine, 2010; van der Meer et al., 2017).

Societal Views

The men agreed that people see only their SCI when they first look at them, and agreed that they have been affected by the misconceptions that society has about men who live with a SCI. The men also had their own misconceptions about living with a SCI that they had to overcome after injury.

In general, the men agreed that dating was not worth the effort due to the amount of time they spent explaining their injury to a new potential partner only to find out that the person was not interested

anyway. The men did not reach a consensus on whether it was difficult to have a conversation about how sex works after SCI with a sexual partner, or potential sexual partner, but many men answered that it was not difficult if you have an understanding partner and if you are an open person by nature. One man wrote, *"sex is sex. If you're not talking to your partner about it, you're not going to enjoy each other or make each other happy in their ways."* Another man shared, *"time needs to be taken to talk about sex and everything that goes along with it post-SCI."* The men did not reach a consensus regarding whether they spent a lot of time educating their partners about sex after SCI and responses were based on personal preference. One man shared, *"I do not spend much time explaining, I try to focus on what I can do, not what I can't."* This is in line with Talbot (1971), who wrote, "*it is more important to concern ourselves with what is left than with what has gone."* Participants agreed that people may not want to date a man with SCI because they do not want to become his caregiver. Men also agreed that educating society about what it means to live with a SCI could improve the dating experience. As an additional comment, one man shared, "*the biggest obstacle I face as a man with an SCI is being seen as sexual. This needs to be addressed to society more. We are the same, we want the same things, we are viable sexual partners."*

Self-View

Participants agreed that men with SCI are viewed as less masculine than men who are able-bodied. They also agreed that the way they viewed their own masculinity had changed post-injury.

Physical changes due to SCI are, unsurprisingly, associated with shifts in self-perception (Romeo et al., 1993). Sexual difficulties not only affect sexuality, they also affect one's identity and self-worth (Stein et al., 2018). Consistent with Reel and Davidson (2018), the participants in this study agreed that sexuality after SCI comes with emotional risks and risks to self-esteem including rejection, embarrassment, shame, disappointment, failure and negative self-view. A consensus was reached and the men agreed that at some point since their injury, they had compared their body to that of an able-bodied man, questioned their

ability to attract a partner, questioned what would make them attractive to a partner, or potential partner, and had avoided approaching a new potential partner post-injury for fear of being rejected. One man commented, "*Prior to being in a committed relationship I was very fearful and anxious about engaging in sexual relationships. I did not believe I was capable of attracting a desirable mate and that my bodily functions would interfere."* Similarly, women with SCI have also questioned whether they could be desired sexually (Leibowitz & Stanton, 2007).

Dependency after SCI may evoke childlike feelings and affect a man's identity or sense of self (Tepper, 1999). The men in this study reported that changes to their level of independence, as well as changes to their level of confidence had, at some point, both negatively affected their self-esteem. The men agreed that decreased self-esteem had a negative effect on sexuality.

Generally speaking, the men reported that they did not think they would have to settle in terms of the partner they would end up with. One participant explained, *"I would prefer to remain single than to settle for someone I was not really interested in."* In contrast, another participant shared, *"I feel I am unable to attract the same type of partner since my SCI."*

Information and Education

Consistent with Kathnelson and colleagues (2020b) the men in this study strongly agreed that it was *important* to receive information about sex after SCI, and strongly agreed that they *wanted* to receive information about sex post-injury. The men agreed it would be beneficial to receive information regarding both the physical aspects of sexuality, as well as the psychological and emotional aspects of sexuality. It was also agreed that increased sexual education after SCI could lead to increased sexual satisfaction.

Responses varied with regards to whether the men were satisfied with the amount of information they received regarding sexuality after SCI. More men reported that they were not satisfied than reported being satisfied, and it was noted that in their experience, some clinicians seemed to find sex awkward to discuss. However, one man shared that many of his peers and healthcare providers were open and helpful, and another man commented that he had access to specialized SCI sexual health clinicians that provided excellent education and clinical support. Additional remarks included that it is up to the individual with SCI to ask the right questions and take responsibility for their own sexuality; that they should not rely on others to *"spoon feed"* them the information, and that everyone is different so they need to seek out information on their own.

There was no consensus regarding whether the men were satisfied with the number of resources available for sex after SCI, though a higher number of men (64%) reported being unsatisfied than were satisfied. One participant who was satisfied stated, *"the resources are out there if you choose to search for answers to your questions."* Participants mentioned that peer mentors were a good resource. Healthcare providers should be aware of existing resources and should enlighten their patients on where and how to access them. Also consistent with Kathnelson and colleagues (2020b), the men agreed that sexual education was not a priority of their healthcare providers when they were in rehabilitation; they agreed that most of their knowledge on the subject came from their own research, not from their healthcare providers. The men generally agreed that their healthcare providers were not knowledgeable about sex after SCI, but were divided on whether their healthcare providers were comfortable discussing sex after SCI. Some comments included, *"healthcare providers have no actual clue about sexuality with disability"* and *"it never feels like they [healthcare providers] care."* One participant noted that he *"can't tell how comfortable they [healthcare providers] are [discussing sex after SCI]."* Aligning with previous work (Kathnelson et al., 2020b), participants agreed that the information they received from their healthcare providers was too clinical and was missing a sense of personal experience that comes from actually living with a SCI. Though a consensus was not reached, many of the men (64%) reported that the resources available for their partners to learn about sex after SCI were inadequate. Men who responded against the popular

opinion provided the rationale that *"online resources are readily available, if your partner chooses to look for them."*

An identified hurdle for discussions about sexuality in healthcare settings is an uncertainty of whose responsibility it is to bring up the topic (Pascual, Wighman, Littooij & Janssen, 2019; Southard & Keller, 2009; Stead, Fallowfield, Brown & Selby, 2001). Patients may be anxious or embarrassed to bring up this issue with their healthcare providers and may not know with which healthcare provider they should have this discussion (Elliott et al., 2017). Patients often wait for their healthcare providers to begin discussions about sex, but due to healthcare provider barriers including a lack of knowledge, lack of comfort and lack of clarity, the topic of sexuality may not be raised (Kathnelson et al., 2020b; Pieters et al., 2018). A recent study found that 24 out of 25 surveyed nurses felt that they required specific training on starting a conversation about sex with their patients (Pascual et al., 2019). Integrating and building the topic of sexuality into patient rehabilitation schedules and programs may be a mechanism to ensure the topic is addressed while eliminating the question of who should initiate the conversation (Kathnelson et al., 2020b; Pascual et al., 2019; Simpson, et al., 2012). Having a physical space where these discussions can take place privately may also facilitate conversations about sexuality (Pascual et al., 2019).

Acceptance

Corroborating previous work from Kathnelson and colleagues (2020b), the men in the current study agreed that they became more accepting of their injury with increased time since injury, and that positively adjusting to sexuality post-injury contributed to their personal growth. As an additional comment, one man shared, "*becoming comfortable with your disability is key to a happy and healthy sex life."* Acceptance by others also facilitated adjustment to sexual life, and life in general post-injury: *"after being in a very committed relationship, feelings of loneliness, anxiety, shame, and frustration have all subsided. There is still frustration about decreased sensation in the sexual organ, as well as pain and spasticity, however, I am better adjusted*." McAlonan (1996) also found that time, experience and

supportive partners were vital to adjustment, acceptance and a fulfilling sexual life for individuals with SCI. Rehabilitation services should aim to support and enhance men's acceptance of their new life post-injury to improve their sexuality, and overall QOL (Aaby, Ravn, Kasch & Anderson, 2020). Conversations with men living with SCI and who have preserved a positive view of their sexuality may also be beneficial for newly injured men (Tepper, 1999).

Rate and Rank

Body image issues that were most often a concern during sexual activities as identified by ≥50% of participants included: flaccid penis, loss of muscle tone, larger stomach and always being in a seated position. Participants were less often concerned about atrophied legs, pressure sores, not being able to wear certain clothes and scars from injury or surgery.

The most common fear that prevented men from participating in sexual activities was the fear of bladder incontinence (50%). Other issues identified by the men included bowel incontinence, autonomic dysreflexia, pain, spasticity and getting hurt, though each was identified by less than 50% of participants.

Frustration was the most commonly experienced emotion after SCI, which affected the sexuality of 80% of participants. Other emotions affecting sexuality that were identified by ≥50% of participants included depression, loneliness, embarrassment and exhaustion/fatigue. Emotions experienced by less than 50% of participants which affected sexuality included: anger, amazement, pride, anxiety, mourning (sadness) and shame. A study by Romeo and colleagues (1993) compared the psychosexual functioning of men with SCI to an able-bodied group of men using the Psychological Symptoms Scale of the Derogatis Sexual Functioning Inventory (DSFI) and found the group with SCI reported significantly higher levels of psychological distress than the men without SCI. Intact sexual desires coupled with altered sexual performance can be a source of frustration, shame and distress due to the negative impact on a man's

sense of masculinity (Rutagumirwa & Bailey, 2017). Additionally, unsuccessful sexual endeavors after SCI may lead to anger, frustration and relationship conflict (Tepper, 1999). In this study, positive sexual experiences were said to increase confidence (65%), lead to increased participation in sexual activities (65%) and have a positive effect on overall QOL (60%). Table 11 outlines body issues and sexual experiences.

Table 11: Body Issues and Sexual Experiences

	Percent Agreement
Body image issues that I have been concerned about include:	
Flaccid penis during sexual activities	80%
Loss of muscle tone	65%
Larger stomach	60%
Always being in a seated position	50%
Atrophied (smaller) legs	35%
Pressure sores	30%
Not being able to wear certain clothes	15%
Scars from injury/ surgery	5%
A fear of the following issues has prevented me from participating in sexual activities:	
Bladder incontinence	50%
Bowel incontinence	35%
Autonomic dysreflexia (high blood pressure)	20%
Pain	20%
Spasticity	15%
Getting hurt	5%
I have experienced the following emotions since SCI that affect my sexuality:	
Frustration	80%
Depression	55%
Loneliness	50%
Embarrassment	50%
Exhaustion/ fatigue	50%
Anger	45%
Amazement	35%
Pride	35%
Anxiety	30%
Mourning (sadness)	30%
Shame	25%
Negative sexual experiences after SCI:	

Lead to avoidance (decreased participation) in sexual activities	45%
Decrease my confidence	35%
Have a negative effect on my overall quality of life	25%
Positive sexual experiences after SCI:	
Increase my confidence	65%
Lead to increased participation in sexual activities	65%
Have a positive effect on my overall quality of life	60%
Help me accept my injury	40%
Give me hope for the future	35%

The most popular response regarding when the men would like to receive information about sexuality was while in rehabilitation (75%), followed by wanting the delivery of information to remain ongoing (65%). Participants in a study by Northcott and Chard (Northcott & Chard, 2000) who had lived with SCI for many years still felt the need for sexual supports which is consistent with the identified need for ongoing information regarding sexuality reported in this study.

Participants' top choices regarding who they would like to receive this information from were relationship counsellors, and other men with SCI (both 65%). The two bottom choices were nurses (35%) and occupational therapists (25%). None of the men reported that they did not want to receive information about sex after SCI. Consistent with other studies (Kathnelson et al., 2020a; Pascual et al., 2019), the participants in this study agreed that having a sexologist or sex therapist would be a beneficial addition to their rehabilitation team.

The men preferred to be educated about sexuality through conversation rather than by reading an educational resource. The top choices regarding how the men would like to receive information about sexuality after SCI were via conversation with a healthcare provider (75%), followed by conversation with another man with SCI (70%). The two bottom choices were via pamphlet (40%) and book (30%). Table 12 outlines the preferences for delivery of information.

Table 12: Information about Sex after SCI

	Percent Agreement
The best time to receive information about sex after SCI is:	
While in rehabilitation	75%
Ongoing	65%
0-6 months after injury	45%
6-12 months after injury	40%
Immediately after injury and again once you are back in the community	30%
Immediately after injury	25%
1-2 years after injury	20%
More than 2 years after injury	20%
I do not want to receive information about sex	15%
I want to receive information about sex after SCI from:	
Relationship counsellor	65%
Another man with SCI	65%
Doctor	55%
Physiotherapist	40%
Psychologist	40%
Nurse	35%
Occupational therapist	25%
I do not want to receive information about sex	0%
I would like to receive information about sex after SCI in the following way(s):	
Conversation with healthcare provider	75%
Conversation with another man with SCI	70%
Internet	55%
Video	50%
Group discussion	45%
Pamphlet	40%
Book	30%
I do not want to receive information about sex	5%

Strengths, Limitations and Future Directions

This study included a broad range of participant experiences from across Canada. This provided a comprehensive insight into the sexuality of men with SCI of different ages, injury levels, injury

classifications, durations since injury, relationship statuses and from different areas within the country. Through utilization of the Delphi Method, anonymity of participants may have reduced the pressure to conform their responses to those of the group. The feedback participants received throughout the study may have deepened insights into their own sexuality and helped validate and normalize their own concerns about sexuality after SCI by discovering that others shared similar experiences.

Five participants were lost over the three rounds, with 15 of the initial 20 men completing the entire Delphi process. Attrition is a known concern associated with the Delphi Method, and many guidelines recommend using two rounds of surveys to prevent response fatigue and participant burnout (Walker & Selfe, 1996). The present investigation tasked participants with completing three rounds to obtain a deeper understanding of survey items, but this may have contributed to participant loss. Moreover, recruitment proved to be a challenge and men who were among the first to complete round one of the survey had additional time elapse before receiving the second survey, which could have also affected participant retention. Despite the loss of five participants from round one to round three, a final sample size of 15 men after three rounds of the survey remains within recommended guidelines (Ludwig, 1996).

Studies about sexuality may attract participants who are open and liberal in their views of sexuality as they may be more comfortable participating in studies about sex. Participants in the current investigation were self-selected, and individuals from cultures and ethnic backgrounds that are less liberal towards sexuality and those who practice religions with restrictive views on sexuality (i.e., stringent views on sexual relations outside of marriage, different sexual orientations, masturbation, etc.) may not have volunteered to participate. The results of this study may not capture the views of such individuals.

There is a known link between mood and sexuality, and negative thoughts, feelings and emotions often have an adverse effect on sexual functioning (Pieters et al., 2018). Emotions experienced by the participants in the investigation, including depression, loneliness, embarrassment and exhaustion/fatigue,

as well as the changes to self-view experienced by participants warrants further investigation and should be considered in rehabilitation services (Willmuth, 1987).

While there has been a focus on the physical aspects of sexuality for men living with SCI (Anderson et al., 2007), sexuality is also comprised of psychological, emotional, sociocultural and interpersonal factors that must be explored (Henze,l Berzins & Langford, 2017; Sunilkumar et al., 2015). Considering the findings from this study and others (Consortium for Spinal Cord Medicine, 2010; Elliott et al., 2017; Henzel et al., 2017; Kathnelson et al., 2020b; Pascual et al., 2019; Pieters et al., 2018) there is ample support for the importance of utilizing a biopsychosocial approach in conjunction with a multidisciplinary team to deliver a comprehensive sexual health rehabilitation and education program to individuals living with SCI.

Conclusions

Sexuality is, and consistently has been, established as an area of utmost importance for individuals with SCI, and that continues to be relevant long after injury (Aikman et al., 2018; Elliott et al., 2019; Simpson et al., 2012; van der Meer et al., 2017). However, this is inconsistent with the reported experiences of men with SCI indicating a perception that this issue is of low priority to healthcare providers and that little attention is given to sexual health education for men after SCI, resulting in a disparity in care (Aikman et al., 2018; Elliott et al., 2019; Post & van Leeuwen, 2012; Simpson et al., 2012;) that has negatively affected QOL for these individuals (Simpson et al., 2012).

Sexual adjustment after SCI is connected to body-image, self-esteem and psychological well-being (Romeo et al., 1993), and sexual capability is important to one's psychosocial rehabilitation post-injury (Talbot, 1971). Society communicates and reinforces harmful myths about sexuality, disability and masculinity, and interventions should be implemented to change negative attitudes and strengthen

positive beliefs regarding sexuality for men after SCI. In doing so, societal norms and emotional responses may be amended for men with SCI, their healthcare providers and the community as a whole (Fisher & Fisher, 1998), improving the landscape of sexual adjustment for this population. A comprehensive sexual health program that supports sexual adjustment from both the physical and psychosocial perspectives is necessary for enhancing sexual enjoyment post-injury (Tepper, 1971) and should be implemented as the standard of care for sexual health in the future.

CHAPTER 5: UTILIZING THE DELPHI METHOD TO ASSESS ISSUES OF SEXUALITY FOR MEN LIVING WITH SPINAL CORD INJURY: A HEALTHCARE PROVIDER PERSPECTIVE

The work in this chapter reflects the work of the candidate with minimal contribution, suggestion and editing from the supervisor and the committee.

Abstract:

This study aimed to uncover important issues regarding sexuality, self-view, societal-view, and sexual health information and education for men after spinal cord injury (SCI) from the perspective of the healthcare provider. Using the Delphi Method, a panel of expert judges including 13 healthcare providers (seven physiotherapists, three registered nurses, two occupational therapists and one physician) who work with individuals living with SCI in Canada completed a series of three questionnaires in an attempt to reach a consensus on previously identified issues. It was agreed that SCI affects physical and psychosocial aspects of sexuality, that psychological and emotional components of sexuality increase in importance post-injury and that healthcare providers are not confident in their ability to effectively counsel their patients on issues of sexuality. When considering previous research that questioned men with SCI on similar issues, healthcare provider perceptions were matched on a number of items, but were not consistent in all areas. Healthcare provider perceptions of issues regarding sexuality for men with SCI should be aligned with patient perspectives to facilitate appropriate support and resources. Healthcare providers should assist patients in exploring new ways to experience sexuality that extend beyond sexual intercourse.

Introduction

Sexuality is a fundamental characteristic of being human, and all people have the right to experience sexuality in a pleasurable and fulfilling manner (WHO, 2020). Sexuality is important for connecting with oneself and with others in a deep and meaningful way, and has been consistently reported as an area of

uppermost importance for individuals living with spinal cord injury (SCI) (Anderson, 2004; Sakellariou & Sawada, 2006; Siösteen et al., 1990). Sexuality continues to be a priority for this population despite physiological changes resulting from the injury that often affect sexuality and sexual function (Elliott et al., 2019). Healthcare providers are aware of the importance of sexuality for their patients and have identified sexuality as an integral component of rehabilitation for individuals living with SCI (Connie, Christie, Hammond, Smith, 1979; Evans, 1985; Gianotten et al., 2006; Pascual et al., 2019). In a study of 25 nurses working with patients having SCI, 100% agreed that sexuality was an essential part of life (Pascual et al., 2019). However, sexuality continues to be inadequately integrated into rehabilitation programs (Elliott et al., 2019; Pieters et al., 2018; Stein et al., 2018).

Discrepancies may exist between the evaluation and priority of topics across many aspects of life amid patients and professionals, including healthcare providers and researchers (Grant-Pierce, Miles & Hills, 1998). It is necessary to consider the voice of the patient in order to effectively develop sexual rehabilitation practices (Elliott et al., 2019). Previous work has leveraged the results of a series of surveys distributed to an expert panel of 20 men living with SCI in Canada to reach a consensus on important issues regarding sexuality from the perspective of the patient (Kathnelson, Kurtz Landy, Tamim, Ditor & Gage, 2021). Using the Delphi method, the current study aimed to uncover important issues regarding sexuality for men after SCI from the perspective of the healthcare provider.

Materials and Methods

Participants and Recruitment

A Delphi panel is comprised of a small number of expert participants (Skulmoski et al., 2007). There are no set standards or agreed upon number of panelists required for a Delphi study (Akins, Tolson & Cole, 2005; Thangaratinam & Redman, 2005; Trevelyan & Robinson, 2015), and the size of the panel is often informed by the research topic, and the time and resources available (Akins et al., 2005). It has been

suggested that six to 12 panelists are ideal for a Delphi study (Hogarth, 1978). Research in healthcare using the Delphi method has most commonly been conducted with a sample size of 10 or more (Akins et al., 2005), though five to 10 panelists having different specialties or from different professions is appropriate (Delbeq et al., 1975; Moore, 1987; Uhl, 1983;). Additionally, it has been suggested that a heterogenous panel is superior to a homogenous group (Powell, 2003; Somerville, 2007). Previous Delphi studies in health research have used panels of five healthcare professionals (Malone et al., 2005), six primary care providers (Strasser, London & Kortenbout, 2005), 10 health experts from various fields (De Vet, Brug, De Nooijer, Dijkstra & De Vries, 2005), 11 nurses (Wilkes, Mohan, Luck & Jackson, 2010), and 13 nurses (Mannix, 2011). Based on these criteria, consideration of the sensitive nature of the subject, the demand on the panelists to participate in a survey at three time points and the heterogenous group of healthcare providers with varying professional titles, a panel of 13 experts was recruited.

Individuals were eligible to join the expert panel if they were able to communicate in English and were currently providing healthcare in Canada to individuals who live with a SCI. Panel members were recruited at a national SCI conference (Canadian Spinal Cord Injury Rehabilitation Association) that was held in Ontario, Canada in 2019 where a recruitment message was sent to all attendees, and at an international SCI conference (American Spinal Injury Association) held in Hawaii, USA in 2018. Participants were also recruited by word of mouth. All participants who enquired about the study were invited to participate.

Ethics approval was obtained from the York University Research Ethics Board and from the Brock University Research Board.

Data Collection

The Delphi Method was employed and utilized an iterative process in which three rounds of online questionnaires were distributed to an expert panel of healthcare providers in an attempt to achieve a consensus on survey items (Delbeq et al., 1975). A URL link to the survey which was hosted in

Qualtrics^{XM}, an online program used to obtain feedback from participants via automated workflows, was e-mailed to participants. Delphi studies commonly involve two or three rounds of questionnaires. Increasing the number of rounds contributes to participant fatigue and a subsequent rise in drop-out rates among study participants is often observed (Keeney et al. 2001; Thangaratinam & Redman, 2005).

All panelists were required to provide informed consent prior to participating in each round of the survey to ensure consent was ongoing. In every round, the first page of the online survey contained a display logic that took the participant to question one of the surveys only if (s)he chose the response providing his/her consent to participate. In the event that a participant selected the response that did not provide his/her consent to participate, (s)he would have been directed to a page thanking him/her for their time and then then prompted them to exit the survey, however this did not occur. Upon completion of the surveys, panelists were e-mailed a $10 gift card as a thank you for their time.

In the first round, panel members received a structured questionnaire based on the Delphi survey distributed to men living with SCI (Kathnelson et al., 2021) that had been reformatted to obtain the opinions of healthcare providers who work with men living with SCI (refer to appendices). Healthcare providers were asked to denote their level of agreement with each item in the survey using a seven-point Likert Scale ranging from strongly agree to strongly disagree. Panelists were also asked to rate and rank several items in order of importance. Three open-ended questions were made available allowing healthcare providers to further explain their responses from Likert Scale questions, and allowing them to voice any concerns they may have had with the survey questions.

In the second round, panelists were provided with a list of the items that had reached a consensus in the previous round. They also received a questionnaire that had been modified based on the feedback obtained from round one that contained the remaining items that had not reached a consensus. Panelists were provided with information regarding their ratings from the previous round in relation to the unidentified ratings of the other panelists. Using this information, panelists had the opportunity to adjust their scores to enable ratings to move towards a consensus (Skulmoski et al., 2007). This round offered four opportunities for healthcare providers to provide written responses to open-ended questions.

In the third and final round, panelists received a list of the items that had reached a consensus in the previous round, a modified questionnaire based on the open-ended responses from round two that contained the remaining items that had not yet reached a consensus, and information about individual ratings compared to group ratings. This was the final opportunity for panel members to revise their judgements. If a rating remained outside the group majority, the panel member was asked to specify his/her reason(s) for remaining against the general agreement.

After three rounds of consultation, the items reaching a consensus reflected the opinions of healthcare providers regarding sexuality for men after SCI.

Data Analysis

Consensus was defined as ≥70% of responses occurring in either the positive end (strongly agree, agree or somewhat agree) or the negative end (strongly disagree, disagree or somewhat disagree) (De Villiers et al., 2005; Meshkat et al., 2014; Sumsion, 1998). Strong agreement was defined as ≥70% of responses occurring in ether the high positive end (strongly agree or agree) or the high negative end (strongly disagree or disagree) (De Villiers et al., 2005; Meshkat et al., 2014; Sumsion, 1998). Data analysis used measures of central tendency (mean and mode) to demonstrate total group ratings. Using these measures, the level of consensus was determined, as well as whether convergence, or a shift towards central tendency and thereby an increase in the strength of the agreement, was achieved from round to round (Hasson et al., 2000; Holey et al., 2007; Hsu & Sanford, 2007). Content analysis was used to analyze qualitative data generated by open-ended questions (Skulmoski et al., 2007). Qualitative data were read repeatedly, and prominent concepts were recorded. Codes denoting these core concepts were derived from the data and were organized into categories that described the comments and opinions of the panelists (Hsieh & Shannon, 2005).

Results

Participants

Thirteen healthcare providers from across Canada who were able to communicate in English and who worked with patients living with SCI were recruited to form the expert panel. The healthcare providers included 11 females and two males between the ages of 21 and 60, and included seven physiotherapists, three registered nurses, two occupational therapists and one physician. Years in practice ranged from <1 year to 25 years. All of the healthcare providers identified as heterosexual. Of the 13 panel members at study onset, 11 completed all three rounds of the Delphi survey (85%). Table 13 outlines the participants' demographic and professional characteristics.

Table 13: Participant Demographic and Profession Information

Age group	**Percent**
≤20	0%
21-30	15%
31-40	46%
41-50	31%
51-60	8%
≥61	0%
Gender	**Percent**
Male	85%
Female	15%
Sexual Orientation	**Percent**
Heterosexual	100%
Profession	**Percent**
Occupational Therapist	15%
Physician	8%
Physiotherapist	54%
Registered Nurse	23%
Years in Profession	**Percent**
<1	8%
1-5	23%
6-10	23%
11-15	15%
16-20	23%

21-25	8%
≥26	0%

Round One

Thirteen surveys were distributed and completed by the healthcare providers. In this round, 41 of 60 items reached a consensus (68.3%). Of those 41 items, 32 (78%) reached a level of moderate agreement with ≥70% of responses in either the positive end (strongly agree, agree or somewhat agree) or the negative end (strongly disagree, disagree or somewhat disagree). Nine items (22%) reached a level of strong agreement with ≥70% of responses in either the high positive end (strongly agree or agree) or high negative end (strongly disagree or disagree) (De Villiers et al., 2005; Meshkat et al., 2014; Sumsion, 1998). Table 14 lists the items that reached a consensus in round one.

Table 14: Items Reaching a Consensus in Round One

Question	**Level of Agreement**	**Percent Agreement**
Men with SCI believe that sex is both a physical and psychological/ emotional experience	Strong agreement	84.6% high positive 100% positive end
Men with SCI believe that sexuality is about more than just sex	Strong agreement	92.3% high positive 100% positive end
Men with SCI believe that sex involves more than just penetration	Moderate agreement	38.5% high positive 92.3% positive end
Men with SCI think that emotional closeness with a partner during sex is more important after their injury	Moderate agreement	53.8% high positive 92.3% positive end
Men with SCI think the sexual experience is more enjoyable when there is an emotional/ psychological connection with a partner rather than just a physical connection	Strong agreement	70% high positive 100% positive end
Men with SCI believe that finding new ways to experience sexual satisfaction is more important after injury	Moderate agreement	61.5% high positive 100% positive end

Men with SCI believe that open and honest communication with a partner about sex is more important after their injury	Moderate agreement	61.5% high positive 76.9% positive end
Men with SCI say they get sexual satisfaction through their partner's sexual satisfaction	Moderate agreement	23.1% high positive 70% positive end
Men with SCI say the way they view their own masculinity has changed since their injury	Moderate agreement	61.5% high positive 92.3% positive end
Men with SCI think that people only see their SCI when they first look at them	Strong agreement	70% high positive 100% positive end
Men with SCI say they avoid approaching new potential partners because they are afraid of being rejected	Moderate agreement	53.8% high positive 84.6% positive end
Men with SCI report that they have questioned their ability to attract a partner	Moderate agreement	53.6% high positive 92.3% positive end
Men with SCI report that they are afraid they will have to settle in terms of the partner they end up with	Moderate agreement	46.1% high positive 84.6% positive end
Men with SCI think that dating is not worth the effort because they spend a lot of time explaining their injury and then the person is not interested anyway	Moderate disagreement	38.5% high negative 76.9% negative end
Men with SCI say they are afraid of letting their partner down sexually	Moderate agreement	38.5% high positive 70% positive end
Men with SCI report having a fear of failure when in a sexual situation	Moderate agreement	30.8% high positive 76.9% positive end
Men with SCI feel that changes in their body functions since injury have negatively affected their sexual life	Moderate agreement	53.9% high positive 76.9% positive end
Men with SCI feel that changes in their sexual function since injury have added stress to their relationships	Moderate agreement	53.9% high positive 100% positive end
Men with SCI feel that changes to their level of independence after SCI have negatively affected their self-esteem	Moderate agreement	46.2% high positive 84.6% positive end
Men with SCI feel that changes to their level of confidence after SCI have negatively affected their sexuality	Moderate agreement	38.5% high positive 84.6% positive end
Men with SCI feel that having to monitor their body during sexual activities takes away from the sexual experience	Moderate agreement	30.8% high positive 76.9% positive end

Men with SCI think that increased planning in their daily life due to injury has had a negative effect on their sexual life	Moderate agreement	23.1% high positive 70% positive end
Men with SCI think that decreased spontaneity in their sexual life due to injury has had a negative effect on their sexual life	Moderate agreement	38.5% high positive 84.6% positive end
Men with SCI feel like something is missing from their life when they think about their sexual experiences now compared to before injury	Moderate agreement	46.2% high positive 70% positive end
Men with SCI believe that positively adjusting to sexuality after injury contributes to their personal growth	Moderate agreement	50% high positive 91.7% positive end
Men with SCI feel that the longer they live with their injury, the more accepting they are of it	Moderate agreement	53.8% high positive 84.6% positive end
Men with SCI say they want to receive education about sex after injury	Strong agreement	75% high positive 91.7% positive end
Men with SCI think it is important to receive education about sex after injury	Strong agreement	90.9% high positive 100% positive end
Men with SCI feel satisfied with the amount of information they received regarding sexuality after injury	Moderate agreement	33.3% high negative 75% negative end
Men with SCI think that it would be helpful to receive information about the physical aspects of sexuality after injury	Strong agreement	75% high positive 100% positive end
Men with SCI think it would be helpful to receive information/ counselling about the psychological/ emotional aspects of sexuality after injury	Strong agreement	75% high positive 100% positive end
Men with SCI report that most of their knowledge about sex after injury came from their own research	Strong agreement	75% high positive 91.7% positive end
Men with SCI feel that sexual education was not a priority of their health care providers when they were in rehabilitation	Moderate agreement	66.7% high positive 91.7% positive end
Men with SCI believe the information provided by health care professionals regarding sex after injury is too clinical	Moderate agreement	50% high positive 83.3% positive end
Men with SCI think the information provided by health care professionals regarding sex after injury is missing the personal experience that comes with actually living with a SCI	Moderate agreement	66.7% high positive 75% positive end
Men with SCI think that increased sexual education after injury could lead	Moderate agreement	66.7% high positive 100% positive end
Men with SCI report spending a lot of time educating new potential partners about sex after injury	Moderate agreement	50% high positive 83.3% positive end

Men with SCI feel that it is difficult to have a conversation about how sex works after injury with a new potential partner	Moderate agreement	50% high positive 83.3% positive end
Men with SCI report being affected by the misconceptions that society has about men who live with a SCI	Moderate agreement	58.3% high positive 100% positive end
Men with SCI report having their own misconceptions about living with a SCI that they have to overcome after their injury	Moderate agreement	58.3% high positive 100% positive end
Men with SCI believe that educating society about what it actually means to live with this injury could improve their dating experience	Moderate agreement	66.7% high positive 91.7% positive end

* Strong agreement/disagreement - ≥70% of responses strongly (dis)agree or (dis)agree
* Moderate agreement/disagreement - ≥70% of responses strongly (dis)agree, (dis)agree or somewhat (dis)agree
***** High positive/negative - strongly (dis)agree or (dis)agree
* Positive/negative end - strongly (dis)agree, (dis)agree or somewhat (dis)agree

Round Two

After distribution, participants were given one week to complete the second survey. Two follow-up e-mail reminders were sent to non-responders (three days after the initial survey distribution and a final reminder the day before the survey would close). Eleven of 13 surveys were returned with an 85% response rate. The 19 items that did not reach a consensus in round one were restructured based on feedback provided by participants (either altering the wording of the question or adding additional response choices), and were examined again in round two. Based on feedback provided in round one, five additional items were developed and were incorporated in round two. A total of 24 items were included in round two, and 14 reached a consensus (58.3%). Twelve items (85.7%) reached a level of moderate agreement with ≥70% of responses in either the positive or negative end, and 2 items (14.3%) reached a level of strong agreement with ≥70% of responses in the high positive end. Table 15 lists the items that reached a consensus in round two.

Table 15: Items Reaching a Consensus in Round Two

Question	Level of Agreement	Percent Agreement
In general, men with SCI think that physical closeness (touching, cuddling, laying together) with a sexual partner is more important than the act of penetration after their injury	Moderate agreement	22.2% high positive 77.8% positive end
In general, men with SCI think that by putting more focus on the emotional/ psychological connection with a partner, the sexual experience can be more satisfying than it was prior to their injury	Moderate agreement	33.3 high positive 88.9% positive end
In general, men with SCI think that they are viewed as less masculine than men who are able-bodied	Moderate agreement	44.4 high positive 100% positive end
At some point since their injury, men with SCI feel that people may not want to date them because they don't want to end up being their caregiver	Moderate agreement	12.5% high positive 87.5% positive end
At some point since their injury, men with SCI feel that changes in their sexual function since injury have caused relationships to end	Moderate agreement	37.5% high positive 87.5% positive end
In general, men with SCI feel that their health care providers are knowledgeable about sex after injury	Moderate disagreement	37.5% high negative 87.5% negative end
In general, men with SCI report that most of their knowledge about sex after injury came from their health care providers	Moderate disagreement	62.5% high negative 87.5% negative end
In general, men with SCI report being satisfied with the resources that are available regarding sex after injury	Moderate disagreement	62.5% high negative 87.5% negative end
In general, men with SCI feel that they are knowledgeable about alternate ways to achieve sexual satisfaction after injury	Moderate disagreement	50% high negative 75% negative end
In general, men with SCI think that there are adequate resources available for their partner to access to learn about sex after injury	Moderate disagreement	62.5% high negative 75% negative end
At some point since their injury, men with SCI have questioned what would make them attractive to their partner/potential partner	Moderate agreement	44.4% high positive 88.9% positive end
At some point since their injury, men with SCI have compared their body to men who do not have a SCI	Strong agreement	88.9% high positive

		100% positive end
At some point since their injury, men with SCI have compared their sexual performance to men who do not have a SCI	Strong agreement	88.9% high positive 100% positive end
In general, decreased self-esteem after SCI negatively affects sexuality for men with SCI	Moderate agreement	44.4% high positive 88.9% positive end

* Strong agreement/disagreement - ≥70% of responses strongly (dis)agree or (dis)agree
* Moderate agreement/disagreement - ≥70% of responses strongly (dis)agree, (dis)agree or somewhat (dis)agree
***** High positive/negative - strongly (dis)agree or (dis)agree
* Positive/negative end - strongly (dis)agree, (dis)agree or somewhat (dis)agree

Round Three

In round three, 11 surveys were distributed and participants were again given one week to complete them. Follow-up reminders were sent to non-responders at the same intervals described in round two with one additional reminder being sent to two participants who had not completed the survey within the one-week time period. All 11 surveys were returned with a response rate of 100% in the third and final round.

The 10 items that did not reach a consensus in round two were restructured based on feedback provided by participants and were asked again in round three. Of these 10 items, six (60%) reached consensus (60%). Four of the six items (66.7%) that reached a consensus were at a moderate level of agreement with ≥70% of responses in either the positive end or the negative end. Two items in this round reached a level of strong agreement (33.3%). Table 16 lists the items that reached a consensus in round three.

After three rounds of surveys, a total of 61 out of 65 items (93.8%) reached a consensus, and four items (6.2%) did not achieve the minimum criteria to be considered a consensus. Table 17 lists the items that did not reach a consensus. Figure 2 outlines the Delphi Process.

Table 16: Items Reaching a Consensus in Round Three

Question	Level of Agreement	Percent Agreement
In general, men with SCI think that sex has less to do with penetration than it did before injury	Moderate agreement	55% high positive 91% positive end
In general, men with SCI say that because of their injury, they are concerned for their physical safety when meeting new people	Moderate disagreement	50% high negative 70% negative end
At some point since their injury, men with SCI feel that changes in the way their body looks after SCI have had a negative effect on their sexuality	Moderate agreement	64% high positive 91% positive end
At some point since their injury, men with SCI feel that cleanliness of their body has been a concern during sexual activities since injury	Strong agreement	73% high positive 82% positive end
At some point since their injury, men with SCI think that their partner is afraid of hurting them during sex	Moderate agreement	55% high positive 91% positive end
In general, men with SCI feel that their health care providers are comfortable discussing sex after injury with them	Strong disagreement	73% high negative 91% negative end

* Strong agreement/disagreement - ≥70% of responses strongly (dis)agree or (dis)agree
* Moderate agreement/disagreement - ≥70% of responses strongly (dis)agree, (dis)agree or somewhat (dis)agree
***** High positive/negative - strongly (dis)agree or (dis)agree
* Positive/negative end - strongly (dis)agree, (dis)agree or somewhat (dis)agree

Table 17: Items that did not Reach a Consensus

Question	Result
In general, men with SCI say they focus more on their partner's sexual satisfaction after their injury	70% neither agree or disagree 30% positive end
In general, men with SCI feel anxious about the side effects of medications that would help them have an erection (eg Viagra, Cialis etc)	45% positive end
In general, men with SCI say they try not to think about sexuality by refocusing their attention on other things	45% positive end

In general, men with SCI have a lower sexual drive than they did prior to their injury	55% neither agree or disagree 36% negative end

* Strong agreement/disagreement - ≥70% of responses strongly (dis)agree or (dis)agree
* Moderate agreement/disagreement - ≥70% of responses strongly (dis)agree, (dis)agree or somewhat (dis)agree
***** High positive/negative - strongly (dis)agree or (dis)agree
* Positive/negative end - strongly (dis)agree, (dis)agree or somewhat (dis)agree

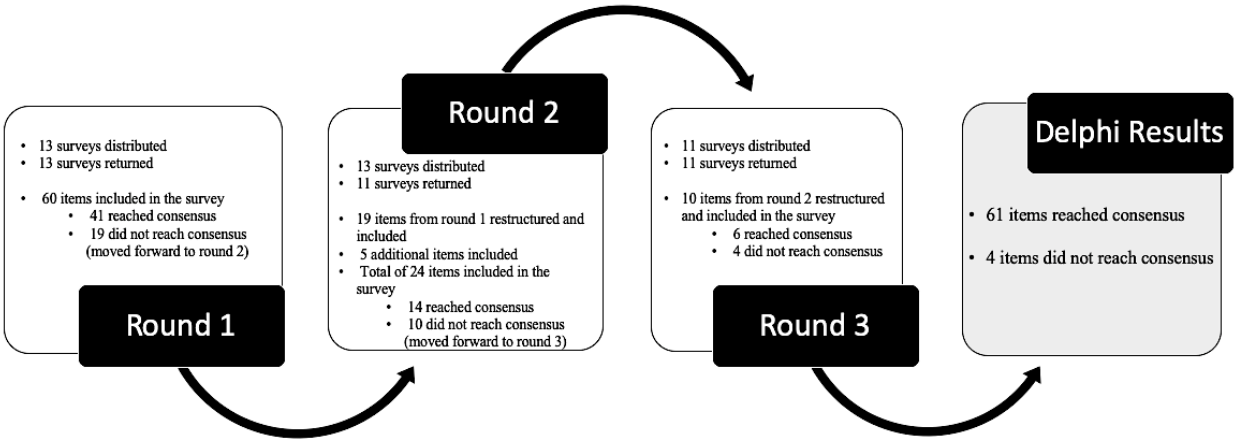

Figure 2: Delphi Process

Discussion

Sexuality

Sex and sexuality do not mean only sexual intercourse, and may be expressed in a variety of ways (Talbot, 1971). In previous research (Kathnelson et al., 2020b, Kathnelson et al., 2021), men with SCI strongly agreed that sex was both a physical, and a psychological and emotional experience. Furthermore, a study by Pascual and colleagues (2019) demonstrated that healthcare providers also agreed that sexuality goes beyond sexual intercourse and includes intimacy, love, relationships and individual

sexuality. This aligns with findings from the present investigation in which 100% of healthcare providers agreed, to some extent, that is, they indicated that they "somewhat agree", "agree" or "strongly agree", that men with SCI believe sex is both a physical, and a psychological and emotional experience. In this study, healthcare providers strongly agreed that for men with SCI, sexuality is about more than just sex. Ninety-one percent of healthcare providers agreed, that according to men with SCI, sex has less to do with penetration than it did prior to injury. One healthcare provider who did not agree wrote, *"I think that like all men, most men with SCI are still quite hung up on penetration, and this remains very important to them after their injury. Although it is helpful for them to think 'outside the box' when it comes to sex, I think it is very difficult for them to shift this perception that sex is more than penetration."* Healthcare providers may underestimate the ability of men with SCI to shift their perceptions of what sex entails. In previous work, men with SCI have specifically called out their desire for healthcare providers to help them *"think outside the box"* and move beyond penetration when it comes to sexuality post-injury (Kathnelson et al., 2020a).

Healthcare providers in this study demonstrated some understanding of the different aspects of sexuality for men with SCI. Previous literature has indicated that with altered physical sexual sensations resulting from SCI, psychological aspects of sexuality may become more important (Leibowitz & Stanton, 2007). Likewise, study participants in the present investigation agreed that for men with SCI, emotional closeness with their partner was more important than it was prior to injury, and that by focusing on the psychological and emotional connection, the sexual experience could be more satisfying than it was prior to injury. Despite the perceived possibility of enhanced sexual satisfaction post-injury, the panel of healthcare providers generally agreed that men with SCI feel that something is missing from their lives when they compare their sexual experiences now to their sexual experiences prior to injury.

This study is one of the first to report healthcare providers' perceptions about how men with SCI perceive their injury to impact their relationships, a topic extremely important to providing appropriate interventions to help men optimize their sexual health. Healthcare providers in our study generally agreed

that men with SCI feel changes to their bodily functions and appearance as a result of SCI negatively affects their sexual lives. Additionally, healthcare providers agreed that men with SCI feel that changes to their sexual function post-injury adds stress to their relationships, and that changes in their sexual function post-injury have caused relationships to end.

Self-View and Societal View

Healthcare providers in our study agreed that SCI changes the way men view themselves as well as the way society views them, indicating that providers have some understanding about the impact of SCI on a man's self-view and the way he is viewed by society. One hundred percent of healthcare providers agreed that men with SCI have been affected by the misconceptions that society has about men who live with a SCI, and that men with SCI also have their own misconceptions about living with a SCI that they must overcome post-injury. All healthcare providers agreed that men with SCI think people see only their injury when they first look at them, and that they are viewed as less masculine than men who are able-bodied. One healthcare provider explained,"*…some men do feel less masculine than able-bodied men when their sexual abilities are altered."* The majority of participants agreed that men with SCI avoid approaching new potential sexual partners for fear of being rejected, and that at some point post-injury, men with SCI feel that people may not want to date them because they do not want to end up being their caregiver, thus they may have to settle in terms of the partner they end up with. Majority of healthcare providers agreed that men with SCI question their ability to attract a partner, and that men with SCI have questioned what would make them attractive to a partner, or potential partner. Questioning one's attractiveness after SCI has been previously identified in the literature (Verschuren et al., 2010), and is consistent with women living with SCI who have also expressed concerns of attractiveness post-injury (Cramp et al., 2014; White et al., 1993). Healthcare providers strongly agreed that at some point since their injury, men with SCI have compared their body to men who do not have a SCI, and that they have compared their sexual performance to men who are able-bodied. Table 18 outlines body issues and sexual

experiences.

Table 18: Body Issues and Sexual Experiences

	Percent Agreement
From the perspective of a healthcare provider who works with men who have a SCI, men with SCI would report that body image issues they have been concerned about include:	
Flaccid penis during sexual activities	92%
Larger stomach	77%
Loss of muscle tone	70%
Atrophied (smaller) legs	54%
Always being in a seated position	46%
Pressure sores	46%
Not being able to wear certain clothes	31%
Scars from injury/ surgery	23%
From the perspective of a healthcare provider who works with men who have a SCI, men with SCI would report a fear of the following issues has prevented them from participating in sexual activities:	
Bladder incontinence	92%
Bowel incontinence	92%
Autonomic dysreflexia (high blood pressure)	62%
Pain	54%
Spasticity	46%
Getting hurt	15%
From the perspective of a healthcare provider who works with men who have a SCI, men with SCI would report the following emotions experienced post-injury affect their sexuality:	
Anger	92%
Embarrassment	92%
Loneliness	85%
Depression	85%
Frustration	77%
Anxiety	70%
Shame	70%
Mourning (sadness)	62%
Exhaustion/Fatigue	62%
Pride	31%
Amazement	15%
From the perspective of a healthcare provider who works with men who have a SCI, men with SCI would report that negative sexual experiences post-injury:	

Lead to avoidance (decreased participation) in sexual activities	45%
Decrease their confidence	35%
Have a negative effect on their overall quality of life	25%
From the perspective of a healthcare provider who works with men who have a SCI, men with SCI would report that positive sexual experiences post-injury:	
Increase their confidence	92%
Have a positive effect on their overall quality of life	92%
Lead to increased participation in sexual activities	85%
Give them hope for the future	70%
Help them accept their injury	54%

Information and Education

Although sexuality has been identified as an activity of daily living by the American Occupational Therapy Association, it is most often not adequately incorporated in rehabilitation practice (Elliott, et al., 2017).Though patients (Kathnelson et al., 2021) and healthcare providers alike believe the topic of sexuality requires additional attention, Gianotten and colleagues (2006) uncovered that neither group tended to initiate discussions about sex or sexuality. Healthcare providers in this study also strongly agreed that men with SCI want to receive information about sex after injury including physical, emotional and psychological aspects, and that receiving sexual education post-injury was important to men with SCI. Despite this, the healthcare providers generally disagreed that men with SCI are satisfied with the amount of sexual information they receive post-injury and disagreed that men are satisfied with the resources that are available to support sexuality post-injury. Additionally, the majority of healthcare providers did not believe that men with SCI think their healthcare providers are knowledgeable about sex after SCI nor comfortable discussing sex after SCI. The healthcare providers' negative perception of their ability to deliver sexual health information to men with SCI has been previously reported in the literature (Aikman et al., 2018; Craven et al. 2012; Elliott et al., 2019; Northcott & Chard, 2000; Pascual et al., 2019; Pieters et al., 2018; Reel & Davidson, 2018). These findings may reflect that many healthcare

providers are uncomfortable providing information about sexuality in general (Zhang et al., 2020), and the unique considerations of men with SCI likely make this task additionally challenging.

Many barriers to addressing sexuality have been reported, including a lack of experience and therefore a lack of confidence addressing sexual function (Pascual et al., 2019; Stein et al., 2018; Zhang et al., 2020), a lack of time, inadequate training, limited availability of resources (Abdolrasulnia et al., 2010; Aikman et al., 2018; Dyer & das Nair, 2013; McCool et al., 2016;), insufficient knowledge, healthcare provider attitude towards sexuality, occupational environment (Pascual et al., 2019), myths and stigmas surrounding sexuality and disability, a lack of clarity regarding whose job it is to address the issue of sexuality (Aikman et al., 2018; Reel & Davidson, 2018) and lack of remuneration (Elliott et al., 2017; New, 2019; Pieters et al., 2018). Healthcare providers in this study generally understood the importance of sexuality and sexual education for men with SCI, however these data suggest that healthcare providers are not prepared to address the topic. Healthcare providers have questioned their own competence to address concerns of sexuality after SCI (Reel & Davisdon, 2018; Stein et al., 2018) and in this study, agreed that patients do not consider them to be comfortable or capable of providing this information. The belief that their patients view them as inept may enhance their insecurities and be an additional barrier to addressing sexuality with their patients.

It is important that healthcare providers are aware of these barriers (Aikman et al., 2018) as they are contributors to the current state of neglect of sexual health topics (Pascual et al., 2019; Reel & Davidson, 2018; Stein et al., 2018). Steps should be taken to enhance healthcare provider knowledge and comfort pertaining to sexuality rather than disregarding the topic (Reel & Davidson, 2018). Healthcare providers should receive adequate education regarding sexuality, and sexual education should be embedded in the rehabilitation schedule (Pascual et al., 2019). To facilitate discussions of sexuality, environmental cues, such as sexual health posters, may be displayed in rehabilitation facilities which may prompt patients to initiate discussions about sexuality while also communicating that the healthcare provider is open to discussing the topic (Fisher & Fisher, 1998). The Consortium for Spinal Cord Medicine (2010) suggests bringing up the topic of sexuality in an open manner using neutral language and without making

assumptions about gender or sexual orientation (Consortium for Spinal Cord Medicine, 2010). In the event that a healthcare provider is not confident in their ability to manage sexual health issues, the healthcare provider should be aware of, and direct patients to, other services, personnel and resources that have the capacity to manage and support their sexual health (Aikman et al., 2018). Though our previous work has shown that men with SCI do consider sexuality to be a rehabilitative priority (Kathnelson et al., 2020a), healthcare providers in this study did not believe that men with SCI feel that sexual rehabilitation is a priority of their healthcare providers.

Survey Considerations

The expert panel of healthcare providers quickly reached high levels of consensus on a majority of the items presented. When a healthcare provider neither agreed or disagreed with a statement, (s)he was asked why this response was chosen. Healthcare providers frequently responded that they had not had these conversations with their patients, stating, *"I feel neutral, haven't had this discussion personally with a patient with a SCI,"* "*I have not had personal experience with this topic with a patient,"* and *"I have not had conversations like this with patients.*" Previous literature has revealed that having conversations about sexuality is difficult for healthcare providers (Zhang et al., 2020), and these results may suggest that conversations between patients and their healthcare providers are failing to address relevant and important topics of sexuality. In a study of 25 nurses, only two reported initiating conversations about sexuality with their patients (Pascual et al., 2019). A majority of those nurses (21) discussed sexuality only when the patient initiated the conversation, and two nurses did not discuss sexuality with their patients at all (Pascual et al., 2019). Forty-four percent of those nurses experienced negative emotions when discussing sexuality with their patients and described it as an "*emotionally difficult task*" (Pascual et al., 2019). Reel and Davidson (2018) suggested that in this situation, the needs and comfort of the healthcare provider are less important than the rehabilitative needs of the patient (Reel & Davidson, 2018). Overcoming this

challenge may require healthcare providers to reflect on, and discuss their own beliefs pertaining to sexuality as well as where their limits are for discussing sexuality with patients (Elliott et al., 2017). Healthcare providers in the current investigation suggested that many of the survey items depended on the individual or couple, relationship status and time post-injury. They shared, *"I do feel that men with SCI vary in their ways of thinking and their perspectives change based on how long after injury you ask them," "I feel that the answers to these questions can change whether a patient is newly injured versus having lived with their injury for a longer period of time- I feel that the person's mindset changes over time, as well as their level of acceptance," "...people with SCI have a wide range of experiences,"* and *"Each patient is different and I try not to make assumptions in my approach."*

One healthcare provider questioned the extent to which their responses have been influenced by their own beliefs and worldviews as opposed to representing the true beliefs of men living with SCI, *"I wonder if most of it [responses to survey questions] is opinion based on their [healthcare providers'] set of beliefs around sexuality in general, as well as around sex and disability."* Another healthcare provider stated that to avoid generalizations, *"I use the sexual rehabilitation framework in a systematic way to try and address patient concerns- this helps to minimize my own biases and assumptions of patient concerns."*

Results for a number of items on the healthcare provider Delphi surveys were consistent with the results of an expert panel of men living with SCI who had previously completed a similar version of the surveys (Kathnelson et al., 2021), however, some discrepancies were revealed. Gaps where healthcare provider responses contradict those of men with living SCI should be addressed and filled.

Rate and Rank

From the perspective of the healthcare providers, men with SCI report that they would most like to receive information about sexuality while in rehabilitation (85%), followed by wanting the delivery of information to remain ongoing (70%). It should not be assumed that because a discussion about sexuality has occurred, the issue has been resolved indefinitely (Siösteen et al., 1990). New sexual challenges may

arise as secondary complications resulting from SCI occur. Required sexual support may evolve over time with changes to relationship status, experience and with age (Hohmann, 1972). For these reasons, the preference to receive information in an ongoing capacity is logical, and continuing education should be made available at follow-up appointments (Myburgh, Fourie & van Niekerk, 2010). From the healthcare provider perspective, men with SCI report wanting to receive this information most from their doctor (92%) followed by another man with SCI (85%). Zero percent of healthcare providers responded that men with SCI do not want to receive information about sex.

According to the healthcare providers, men with SCI prefer to learn about sexuality through one- on-one discussions with a healthcare provider or another man with SCI (77% each) rather than by means of educational resources. Table 19 outlines the preferences for delivery of sexual health information.

Table 19: Information about Sex after SCI

	Percent Agreement
From the perspective of a healthcare provider who works with men who have a SCI, men with SCI would report that the best time to receive information about sex after injury is:	
While in rehabilitation	85%
Ongoing	70%
0-6 months after injury	38%
Immediately after injury and again once you are back in the community	38%
6-12 months after injury	31%
Immediately after injury	7.5%
1-2 years after injury	7.5%
More than 2 years after injury	7.5%
Men with SCI do not want to receive information about sex	0%
From the perspective of a healthcare provider who works with men who have a SCI, men with SCI would report that they would like to receive information about sex after injury from:	
Doctor	92%
Another man with SCI	85%
Physiotherapist	62%
Nurse	54%
Occupational Therapist	54%
Relationship Counsellor	54%

Psychologist	46%
Men with SCI do not want to receive information about sex	0%
From the perspective of a healthcare provider who works with men who have a SCI, men with SCI would report that they would like to receive information about sex after injury in the following way(s):	
Conversation with healthcare provider	77%
Conversation with another man with SCI	77%
Pamphlet	70%
Video	70%
Internet	62%
Group discussion	46%
Book	31%
Men with SCI do not want to receive information about sex	0%

Strengths, Limitations and Future Directions

Previous SCI literature has considered sexual rehabilitation from the perspective of the patient (Kathnelson et al., 2020a; Kathnelson et al., 2020b; Kathnelson et al., 2021), and the current investigation adds information about sexual rehabilitation from the perspective of healthcare provider.

Participants were self-selected and therefore this study may have drawn a sample of healthcare providers with more interest in, or knowledge of, sexuality for men after SCI. Though maximum variation sampling was exercised to allow for a heterogenous sample of participants with differing characteristics (Liamputtong, 2009), the panel was comprised of 50% physiotherapists, 85% females and 100% individuals identifying as heterosexual. It is possible that a more diverse panel may have generated different results.

Both men with SCI (Kathnelson et al., 2020a; Kathnelson et al., 2020b; Kathnelson et al., 2021) and healthcare providers have agreed that finding new ways to experience sexuality beyond penetration is important following SCI. Patients should be reassured that sexuality involves more than just physical sexual intercourse, and other types of physical and emotional intimacy should be encouraged (McAlonan, 1995). Moving forward, sexuality should be included in a checklist of items to discuss with patients. The

checklist will prompt conversations about sexuality, helping to overcome the first barrier which is initiating the conversation. This will ensure every patient has the opportunity to learn about sexuality post-injury, mitigating assumptions and biases which may influence whether or not information about sexual health is offered (McKenna, 2001). Healthcare providers should also be provided with opportunities to assess their own beliefs about sexuality, and their comfort in helping patients explore sexuality in non-traditional ways (Couldrick, 1999). Becoming aware of their biases will aid healthcare providers in suspending their own judgements while working with their patients.

Conclusions

Spinal cord injury will likely affect genital and physical aspects of sexuality, but is unlikely to affect basic human sexual desires or the need for closeness and intimacy (Northcott & Chard, 2000; Willmuth, 1987). Healthcare providers should legitimize and validate their patients' desire and need to be sexually active, (Pieters et al., 2018 ; Reel & Davisdson, 2018) and should support individuals with SCI to view themselves as sexual beings deserving of satisfaction with their sexual lives (Elliott et al., 2019). Healthcare providers must obtain a more complete understanding of the meaning of sexuality in society today to support men with their psycho-social adjustment to life after SCI (Talbot, 1979). Additionally, healthcare providers should be encouraged to promote a broad range of sexual activities (Fisher & Fisher, 1998) to support the evolving meaning of sexuality post-injury (Kathnelson et al., 2020a). Lastly, it is important for healthcare providers to understand the beliefs and needs of men with SCI regarding issues of sexuality, and to align with their patients. This may facilitate relevant discussions about sexuality and may improve healthcare providers' capacity to provide effective counselling and resources.

CHAPTER 6: DISCUSSION

During the phenomenological interview component of this research, it had been challenging to encourage the men to leave the physical descriptions of their sexual experiences behind and discuss sexuality in a different way. Women I had previously interviewed were able to describe their sexuality on a deeper, more emotive level, whereas men in the present investigation tended to defer to a physical means of describing their sexuality post-injury. It was difficult to encourage the men to describe how their sexual experiences had affected them, and what those experiences meant to them. Despite the discovered evolution of sexuality from a purely physical act with a genital focus to a deeper, more intimate experience, the men lacked the language to express this.

Men have been socialized to believe they cannot show, or even have feelings other than anger (Hearn, 1993; Hooks, 2004). As a result, men may not be in touch with, or know how to access the emotional side of themselves. A number of men in the phenomenological study expressed that they had never discussed sexuality in this manner which may be correlated to the lack of related education and resources available. After much probing, and once the men learned how to open up, the stories poured out. They were personal, intimate, deep, rich, thoughtful, revealing and honest. On a personal level, I am humbled that the men trusted me enough to share their most personal encounters regarding such a delicate subject, and allowed themselves to be vulnerable and share their emotions with me. I was deeply affected by all of the interviews and often felt emotionally drained, as though I could not possibly witness the distress and pain of another man during another interview. Interestingly, a number of the men revealed that expressing themselves in this way was “a bit of a relief” and that talking through it was therapeutic as it helped them work through the issues in their own lives.

Sexuality is a complex phenomenon involving both physical and psychological components. Research and education regarding sexuality for men after SCI has more often considered the physical aspects, and sexuality for this population has not been adequately addressed in a holistic manner. As I set out to

explore the missing piece, the psychological and emotional aspects of sexuality for men after SCI, I realized that I also was failing to examine sexuality holistically. It is my opinion that exploring issues after SCI in a holistic way is challenging due to the literal split between the brain and the body. The psychological insight obtained through this series of investigations may be combined with existing information on physical factors to facilitate the consideration of sexuality in a holistic sense.

Men with SCI and Healthcare Provider Results

After three rounds of Delphi surveys, men with SCI reached a consensus on 50 of 65 items (76.9%), and healthcare providers reached a consensus on 61 of 65 items (93.8%). The responses of men with SCI and healthcare providers were consistent on 46 of 65 items (70.8%) where results were reported in the same end (either the positive end signifying agreement, or the negative end signifying disagreement) by both groups. Of the 19 items where the groups' consensus differed, 13 of those (68.4%) were due to one group choosing a positive response and the other group choosing a negative response, and in six instances (31.6%), the difference was due to one group not reaching a consensus in either end. Appendix Q provides information about the Delphi results of the men versus the healthcare providers.

Sexuality

Men with SCI and healthcare providers both strongly agreed that for men with SCI, sex is both a psychological and emotional experience, and that *sexuality* involves more than just *sex*. Both groups agreed that sex involves more than just penetration, has less to do with penetration after SCI and that other types of physical closeness including touching, cuddling and laying together are more important than the act of penetration after injury. This is consistent with a study by Ide and Ogta (1995) who surveyed 102 individuals living with SCI in Japan and found the top two ways in which participants had engaged in sexuality post-injury were through a psychological relationship and by hugging. This is also consistent with previous literature in which Tepper (1999) stated that sexual pleasure and sexual

satisfaction after SCI may be achieved through a number of behaviors beyond traditional sexual intercourse including touching, kissing, oral sex, anal sex and masturbation. In the present investigation, both men with SCI and healthcare providers strongly agreed that the sexual experience is more enjoyable when there is an emotional/psychological connection with a partner rather than just a physical connection, and that emotional closeness with a partner is more important post-injury. An explanation of these findings could be that men have shifted their focus from an area where they now have less control, that being their physical selves, to an area of strength as control of their thoughts remains post-injury.

When asked if focusing on the psychological and emotional connection with their partner could make the sexual experience more satisfying than it was prior to injury, men with SCI in the current investigation did not reach a consensus though the largest occurrence of responses for this group fell in the positive end. Healthcare providers agreed that focusing on this type of connection could make the sexual experience more satisfying for a man with SCI than it had been prior to injury. Physical limitations resulting from SCI will negatively affect sexual activities, but emotional and psychological aspects of sexuality may compensate for physical limitations (Kreuter et al., 1996). As a result, the psychological and emotional connection with a partner may intensify after SCI (Ostrander, 2009). Previous work has found that emotional factors of sexuality are important for maintaining a satisfying sexual life post-injury (Kreuter et al., 1994) and that men with SCI redefine sexuality to encompass a psychological element that elicits satisfaction (Donahue & Gebhard, 1995). Sexual fulfillment and satisfaction are enhanced when there is a strong emotional connection in the relationship (Ricciardi et al., 2007) which is aligned with the views of men and healthcare providers in this study.

Men with SCI moved along a continuum from rejecting a new meaning of sexuality, to acknowledging, but being unable to accept a new meaning of sexuality, to accepting a new meaning of sexuality, masculinity, disability and attractiveness. Increased levels of acceptance seemed to be related to higher ratings of sexual satisfaction, and lower levels of acceptance were correlated with decreased sexual

satisfaction. Men are hindered in moving towards acceptance by having to overcome socially accepted norms of these constructs.

High level cervical and thoracic SCI result in unstable blood pressure (Claydon, Steeves & Krassioukov, 2006) and other cardiovascular abnormalities, including autonomic dysreflexia (AD). Autonomic dysreflexia is a serious and potentially life-threatening consequence of SCI (Spinal Cord Consortium, 2001) characterized by a rapid and extreme increase in blood pressure (Braddom & Rocco, 1991; Bycroft, Shergill, Choong, Arya & Shah, 2005; Consortium for Spinal Cord Medicine, 2001). It is possible for an individual to experience AD while being unaware that they are showing symptoms which is referred to as silent AD (Claydon et al., 2006). Autonomic dysreflexia can be triggered by a number of noxious or non-noxious stimuli below the level of the lesion (Ekland, Krassioukov, McBride & Elliott, 2008). Sexual activity, specifically ejaculation and orgasm, can trigger AD (Consortium for Spinal Cord Medicine, 2010) and having to worry about AD takes away from the enjoyment of the sexual experience. Men in the current investigations reported that the information they received about AD in relation to sexuality was unclear. As a result of problems with blood pressure caused by medications used to facilitate sexual performance, a fear of triggering AD, and a lack of education on the issue, some men conveyed during the interviews that they do not wish to achieve ejaculation or orgasm. An interpretation of these data is that the potential to experience AD may also contribute to the shift of sexuality from a physical experience to a psychologically focused experience post-injury. It is imperative that men with SCI who are at risk for experiencing AD are educated and knowledgeable about the causes, symptoms and consequences, as well as steps for managing an episode of AD should one occur. It must also be noted that while the rehabilitative focus has been on erection and ejaculation, men with SCI may not be interested in either of those events at all.

Consistent with findings from Sioseteen and colleagues (1990), Sakellariou and Sawada (2006) and Ricciardi and colleagues (2007), men with SCI as well as healthcare providers in the present investigation agreed that exploring and finding new ways to experience sexual satisfaction was more important post-

injury. A range of sexual health behaviours should be promoted (Fisher & Fisher, 1998) to support the evolved meaning of sexuality of this population. Research should explore alternative methods for achieving sexual pleasure through the development of psychological techniques (Craven, 2012). It has also been that suggested that involving all available senses including touch, taste, smell, sight and hearing, as well as imagination and past memories may enhance the sexual experience (Anderson, 2007).

During the phenomenological interviews of the current study, men identified being open-minded and exploring sex beyond penetration as very important after SCI. One participant shared that he had become involved with what he described as a "sex-positive" community online. The community was not for individuals with a disability, but for people with different sexual desires, most commonly bondage and discipline, dominance and submission (BDSM). Bondage and discipline, dominance and submission may entertain a culture that is accepting of socially "unacceptable" sexual expressions, such as sex and disability. According to socially accepted norms, men should be sexually dominant thus causing men with SCI to feel inadequate when they have not been able to take control in a sexual setting due to physical limitations resulting from the injury (Sakellariou & Sawada, 2006). Bondage and discipline, dominance and submission is based on communication (Cutler, 2003), and it is the researcher's thought that individuals participating in BDSM may be able to take back power and dominance in a sexual setting through verbal communication and providing commands. Use of verbal commands would allow men with SCI to exert dominance in a sexual setting despite physical limitations. Furthermore, the psychological mind-play involved with BDSM may be in alignment with the evolved meaning of sexuality for this population by bringing to the forefront the psychological aspect. The researcher does not suggest, in any way, physical dominance, bondage or any other aggressive sexual acts associated with BDSM as they could potentially be dangerous for individuals with SCI who may experience AD. The researcher also does not suggest aggressive sexual activities for any vulnerable population, including individuals with SCI, where violence may become an issue. However, verbal commands and communication that would allow a man with SCI to direct his sexual partner may be an option to explore when thinking outside the

sexual box. Research into the possible use of verbal sexual cues in a safe manner where both parties agree may be warranted.

Given the evolved meaning of sexuality which encourages broadening one's sexual scope and exploring new ways to experience sexuality post-SCI, questions regarding the ethical limits of healthcare providers to support their patients in exploring their sexuality should be addressed. Additionally, healthcare providers will have to assess their own perspectives on sexuality and determine appropriate boundaries (Reel & Davidson, 2018).

It should be noted that ejaculation is not the same thing as orgasm, and men with SCI need to be educated on the difference. Orgasm is a psychological experience, and therefore, it is possible to experience an orgasm without ejaculation. Men in the interview component of the present investigation became frustrated and discouraged when they were unable to experience climax in the same way they did prior to injury. It should be reinforced that ejaculation is not a requirement of every sexual encounter, and sexual activity without ejaculation can still be an enjoyable and worthwhile experience (Willmuth, 1987). Men with SCI would benefit from redefining their "*end goal*" during sexual activities, and what constitutes a successful sexual experience.

Both groups in the current Delphi study agreed that men with SCI experience sexual satisfaction through their partners' sexual satisfaction, however, the men strongly agreed with the statement and healthcare providers underestimated the extent to which the men reported experiencing sexual satisfaction through their partners' satisfaction. Previous research has demonstrated that men with SCI obtain sexual pleasure from the knowledge that they have sexually satisfied their partner (Ostrander, 2009) and that physical stimulation paired with the observation of a partner's sexual enjoyment has produced feelings similar to that of an orgasm in men with SCI (Kreuter et al., 1996). In the current study, when asked if men with SCI put more focus on their partners' sexual satisfaction post-injury, the men strongly agreed, however the healthcare providers did not reach a consensus and again, underestimated, or were unaware of, the

shift to partner-centered sexual experiences for men post-injury. This is aligned with previous research which has suggested that individuals with SCI have more concern for their partners' sexual satisfaction than their own (Alexander et al., 1993; White et al., 1993), and that sexually satisfying one's partner is more important than one's own sexual satisfaction after SCI (Low & Tunka, 2000). In-depth interviews with men living with SCI revealed that partner satisfaction had become a principal component of their sexuality post-injury, and a longitudinal analysis of survey results at four time points between inpatient rehabilitation and 18 months after discharge found the participants' highest concern was their partners' sexual satisfaction at all time points (Fisher et al., 2002). A shift to partner-centred sexual experiences in which sexual satisfaction is achieved via the partner's satisfaction has been repeatedly reported in the literature and has been acknowledged again by the participants in the current research, yet healthcare provider perceptions were not reflective of this sentiment. A healthcare provider's focus will be on their patient, and therefore, the provider may not reflect on the importance of the partner. However, the partner should be considered when addressing sexuality in a holistic manner, and the misalignment of healthcare provider assumptions regarding partner dynamics after SCI is an area in which provider education should be improved.

During the phenomenological interviews of the current research, men reported fear that their partner may be made to feel sexually inadequate if the partner was unable to sexually satisfy him. It was clarified that this would not be any fault of his partner, but rather due to his decreased sexual functioning and sensation. It would be easier for a woman to imitate her enjoyment, but typical indicators of male arousal and pleasure including erection and ejaculation which are frequently affected by SCI (Alexander et al., 1993; Hammond & Burns, 2009; Schopp et al., 2007; White et al., 1992) would be more difficult to simulate and may negatively affect the partner's sexual self-confidence if not achieved. Open and honest communication about sex after SCI may be important for communicating such messages to a partner to mitigate this situation. That being said, the interviews revealed that for men living with SCI, explaining how sex works post-injury can be a difficult conversation to navigate with a new potential partner. From

the perspective of the men, it was challenging to find a balance between open and honest communication without sharing an overwhelming amount information in which it becomes too much for the potential partner to handle. Nevertheless, the men shared that explaining these issues upfront is the key to avoiding potentially uncomfortable situations in the moment. Sexual counselling should address partner communication and should provide strategies for disclosing sensitive information about sexuality, as well as provide strategies for managing situations where these messages are negatively received.

Previous research would suggest that sexual desire remains relatively unchanged after injury (Fisher et al., 2002; Siosteen et al., 1990). Dahlberg and colleagues (2007) found that of 92 men with SCI, 86% experienced continued sexual desire, and Rietz and colleagues (2004) found that of 46 men with SCI, 86% rated their sexual desire as very high, high or moderate. Neither men with SCI or the healthcare providers in the current study reached a consensus on whether men had a lower sexual drive post-injury. The men tended to agree more often than they disagreed and healthcare providers most often chose to neither agree or disagree with the statement. In the experience of the researcher, men in the present series of investigations seemed to have less interest in sex than a group of women with SCI who had been previously interviewed (Cramp et al., 2014). A possible explanation is that the penis is the main instrument in traditional views of male sexuality. Frequent problems with obtaining and maintaining an erection after SCI do not align with the views of sexuality that men are accustomed to which may lead to decreased interest in participating in sexual activities. The medical model of care would address this situation with provision of medication for erectile dysfunction, but instead, work should be done to dispel the myth that sex should be centered around the penis (Federici et al., 2019).

Self and Societal Views

Spinal cord injury is a visible disability, meaning it is obvious to others upon initial encounter. Individuals with a visible disability may experience additional stigmatization and social restraints, and may be more likely to be viewed as asexual than individuals whose disability is not visually apparent

(Esmail et al., 2010). Consequently, men with SCI have felt that they are viewed differently by society (Sheldon et al., 2001). When first looking at a man with SCI, both groups in the current study agreed that people see only the injury. Men with SCI and health care providers alike agreed that men with SCI are affected by the misconceptions that society holds regarding this population, and both groups agreed that men with SCI have their own misconceptions about living with a SCI that they must overcome post-injury.

Secondary consequences of SCI may negatively affect one's sense of masculinity or femininity, gender role and sexual appeal (Elliott et al., 2017). In the current study, men with SCI and healthcare providers both agreed that the way a man views his masculinity is changed after SCI, and that men with SCI are viewed as less masculine than men who are able-bodied. Focus group participants have felt that they would no longer be viewed as men if they could not perform sexually (Low & Tunku, 2000).

Society has been programmed to believe that a perfect body is the norm and that a disability is a deviation from that standard (Barnartt, 2010). Both groups in the present study agreed that at some point after SCI, men question what would make them attractive to a potential partner and avoid approaching a new potential partner due to a fear of being rejected which could have implications for establishing social and romantic relationships. During earlier focus group discussions, participants with SCI shared similar feelings of unattractiveness, and believed that no one would want to date them as a result (Low & Tunku, 2000). Women with SCI have also had concerns regarding their sexual-attractiveness post-injury (Cramp et al., 2014; White et al., 1992). Independence, self-esteem and masculinity are closely related in men with SCI (Basson et al., 2003) and a loss of independence, changes to body image and decreased confidence have a detrimental effect on self-esteem that indirectly affect sexual self-view (Elliott et al., 2017; Siosteen et al., 1990). Both groups in the current study concurred with previous literature and agreed that changes to a man's independence, confidence, self-esteem and body image negatively affect his sexuality.

Individuals with a disability are also socialized to subscribe to these detrimental attitudes and beliefs (Hammond & Burns, 2009; Tepper, 2005) about ideal bodies, masculinity, sexuality and disability. Men with SCI must alter their own views of themselves after injury (Sheldon et al., 2001), and counselling to modify one's negative self-view may be useful for this population. Future research should consider the factors that could improve body-esteem and sexual-esteem to refine the way an individual with SCI views themself (New, 2019). Counselling that encourages positive body-image and self-esteem should be offered as part of a sexual heath rehabilitation program (McBride & Rhines, 2000), and counselling to help men unlearn socially constructed and unrealistic myths about masculinity and male sexuality while teaching them accurate information about gender identity and human sexuality (Tepper, 1999) should be employed. Redefining and adapting one's sexual self-concept is essential to positive sexual adjustment after SCI (Ricciardi et al., 2007).

Information and Education

Sexual function has been identified as a top therapeutic priority for individuals with SCI (Anderson, 2004) and is an important factor in the overall rehabilitation of this population (Sheel et al., 2005). Both groups in the present investigation reported that men with SCI want to receive sexual education as part of rehabilitation, and strongly agreed that men with SCI think it is important to receive education about sex post-injury. When asked if increased sexual education after SCI could lead to increased sexual satisfaction, both groups agreed. Similar findings have been identified in previous research in which 190 individuals with SCI were questioned, and participants who rated the amount of sexual counselling they received as sufficient had higher levels of sexual satisfaction than those who did not receive adequate sexual counselling (Valtonen et al., 2006).

When asked if it would be helpful for men with SCI to receive information about the physical aspects of sexuality, and information about the psychological and emotional aspects of sexuality, men in the current study agreed with both, and healthcare providers strongly agreed with both. The physiological and

psychosocial implications of SCI have both a direct and a secondary negative effect on sexual QOL (Elliott 2019) and from a patient perspective, sexual rehabilitation programs that address both physical and psychological aspects of sexuality have been well received (McAlonan, 1995). A psychoeducational intervention for sexuality after SCI was assessed and was found to improve sexual interest, sexual satisfaction, the ability to enjoy sexuality and to reduce anxiety (Federici et al., 2019). Through cognitive behavioural therapy involving role-playing, problem solving, and imagery, participants were guided towards overcoming myths and misconceptions regarding sex and disability, sexual fantasies, masturbation, orgasm, sexual identity, beauty and attractiveness of the body. This approach intended to overcome the medical model view of disability and the idea that sex is limited to the genitalia (Federici et al., 2019). The intervention also aimed to generate new thoughts towards sexuality by further considering feeling and emotion, and creating a new meaning of sexuality (Federici et al., 2019).

Consistent with findings from the present study, a scoping review conducted by Zhang and colleagues (2020) recently found that patients and healthcare providers both believe that sexual health is an important contributor to overall health. However, both groups in the current study acknowledged a lack of resources and a lack of sexual education for this population. Healthcare providers have admitted that they often do not discuss sexual health with their patients even though they believe it is important (Chapman & Spitznagel, 2019), and Zhang and colleagues (2020) found that although healthcare providers viewed sexual health to be important, they viewed it to be less important than other areas of rehabilitation. This is consistent with the present investigation as participants generally agreed that sexual education is not a priority of their healthcare providers during rehabilitation. Both groups also generally disagreed that healthcare providers are knowledgeable about sex after SCI, and with regards to whether healthcare providers are comfortable discussing sex after SCI with their patients, the men did not reach a consensus but healthcare providers strongly disagreed with the statement. These results are aligned with a recent scoping review which revealed that healthcare provider knowledge, comfort and confidence to discuss sexual health with their patients were lacking (Zhang et al., 2020). Given that healthcare providers have

identified sexuality as an important topic but have not considered it their priority, it is possible the lack of prioritization exists due to barriers providing this information, not because healthcare providers view sexuality as unimportant. Literature suggests that a major contributor to the inability of healthcare providers to support the sexual education requirements of their patients is a lack of appropriate training (Lombardi, Del Popolo, Macchiarell, Mencarini & Celso, 2010) which may negatively affect a healthcare provider's confidence in their ability to address topics of sexuality. Furthermore, healthcare providers are aware of their patients' scepticism when it comes to their competency to counsel on this topic which may further enhance their insecurities to address the subject. Instead of avoiding conversations about sexuality that they are not prepared to have, healthcare providers should work to up-scale their own knowledge and comfort to facilitate provision of sexual support for their patients (Reel & Davidson, 2018). Healthcare providers' negative attitudes about their ability to provide sexual health information to men with SCI should be explored in more detail, and an action plan beginning with a sexual education training curriculum to overcome these insecurities should be developed.

Gianotten and colleagues (2006) surveyed 244 rehabilitation professionals and found that majority of healthcare providers felt they were trained insufficiently or very insufficiently to address topics of sexuality (68% from group A [physicians, psychologists and social workers]; 93% from group B [nurses]; 93% from group C [physical therapists, speech therapists and occupational therapists]). Ninety-three percent of healthcare professionals from group A (physicians, psychologists and social workers) believed the topic of sexuality belonged to their discipline, 0% believed it did not belong to their discipline, 32% felt sufficiently trained in sexuality and 71% reported needing to be trained on sexuality. Eighty-seven percent of healthcare professionals from group B (nurses) believed the topic of sexuality belonged to their discipline, 2% believed it did not belong to their discipline, 6% felt sufficiently trained in sexuality and 92% reported needing to be trained on sexuality. In group C (physical therapists, speech therapists and occupational therapists), 48% of healthcare professionals believed the topic of sexuality belonged to their discipline, 30% believed it did not belong to their discipline, 7% felt sufficiently trained in sexuality and

71% reported needing to be trained on sexuality. A study evaluating the education and training of multidisciplinary teams in sexual health found the training significantly improved healthcare providers' ability to have conversations about sexuality, their ability to identify sexual challenges and their knowledge and comfort to address sexuality (Pieters et al., 2018). Training and education to enhance healthcare providers' capability to address sexual health may currently be the missing element (Zhang et al., 2020).

Healthcare providers working in sexual rehabilitation have identified the need for a standardized and multidisciplinary approach to sexuality that incorporates expertise from various disciplines to effectively address the complexity of sexual health (Elliott et al., 2017; Pieters et al., 2018). All parties involved in the rehabilitation team should include sexuality in their scope of care and should be prepared to contribute to a patient's sexual health. Factors affecting sexual function such as pain or AD may be covered by a medical doctor. Motor and sensory issues may be addressed by an occupational therapist or physical therapist, and sexual self-esteem or sexual self-view may be addressed by a psychologist. Using this approach, the responsibility is shared and the various aspects of sexuality are addressed by the appropriate professional (Elliott et al., 2017). Furthermore, by embracing sexual health and incorporating in into rehabilitation, patients may experience fewer feelings of embarrassment, an increased number of opportunities to discuss sexuality with their healthcare providers, have clarity about which healthcare providers address which aspects of their sexual health, and will have that conversation initiated by their healthcare provider. These discussions may relieve patient concerns and provide guidance on moving forward with their sexual lives (Zhang et al., 2020)

Rate and Rank Items

Though men with SCI and their healthcare providers identified a similar order for all body image concerns, the panel of healthcare providers tended to overestimate the occurrence of these concerns compared to what the panel of men reported. When asked to rate the fears that prevent men with SCI from

participating in sexual activities, both groups provided the same order of items (bladder incontinence, followed by bowel incontinence, AD, pain, spasticity and getting hurt) but again, the healthcare providers overestimated the rate at which men with SCI reported experiencing these fears.

Men with SCI reported frustration to be the number one emotion that affects their sexuality, while the healthcare providers perceived anger and embarrassment to be the emotions that most affect a man's sexuality post-injury. While healthcare providers rated pride and amazement as the least frequently occurring emotions, men with SCI ranked these positive emotions above feelings of anxiety, mourning (sadness) and shame. Healthcare providers tended to overestimate the incidence of both negative experiences and negative emotions, and underestimated the occurrence of positive emotions. This may be because healthcare providers tend to see patients with SCI most frequently during rehabilitation or early in their injury before they have had time to learn to positively adjust to living with a SCI. Additionally, healthcare providers would be more likely to see a patient when they are experiencing physical or psychological distress as opposed to during a period of good overall health. Healthcare providers should be made aware of the positive outcomes of individuals with SCI and use that information to encourage their patients during periods of distress. Appendix R outlines information regarding body issues and sexual experiences.

In the current study, men with SCI reported that they would most like to receive information about sex from another man who has a SCI or from a relationship counsellor. Though another man with SCI was the second choice of healthcare providers, relationship counsellor was not a top selection of this group. Only 55% of men with SCI identified a doctor as their first choice, compared to 92% of healthcare providers who selected this option. This is aligned with interview and Delphi results from the present investigation in which participants expressed concern regarding their healthcare provider's ability and willingness to counsel on sexuality. Appendix S outlines the preferences for delivery of sexual health information.

Strengths, Limitations and Future Directions

Strengths

Though sexual health has been validated as a top and enduring priority for men living with SCI, a discrepancy continues to exist between the demand for, and capability to provide, appropriate sexual health support (Craven et al., 2012). This research contributes to knowledge generation through discovery of sexual health concerns and priorities of men living with SCI and their healthcare providers, and provides emerging evidence to support effective change in this area. This research considers the psychological and emotional aspects of sexuality that have been largely overlooked and underexplored for this population, and elucidates the importance of bringing these facts of sexuality to the forefront. A shift in the meaning of sexuality for men after SCI is highlighted, and attention is called to areas of sexuality where healthcare provider perspectives may not align with patient perspectives as a result. Previous research has considered sexuality after SCI from the perspective of the patient, and from the perspective of the healthcare provider, but this study adds a comparative component which allows us to evaluate the level of agreement between the groups as well as identify areas where perspectives need to be brought together. Only when healthcare providers understand the needs of men with SCI in terms of their sexual health will they be properly equipped to support their patients.

Limitations

There are possible limitations for the phenomenological study. Qualitative research utilizes the researcher as an instrument during data collection, and for that reason, the researcher will, to some extent, influence the investigation and the findings. To be transparent, the researcher has provided information about herself to allow the reader to understand how she may have influenced the study (Rutagumirwa & Bailey, 2018). The qualitative interviews were in-depth, and therefore, quite long. Interview questions challenged the participants to push their emotional boundaries on a difficult and sensitive topic which could have led

to fatigue for both the participant and the interviewer. It is possible that responses to questions at the end of the interview guide may have decreased in quality. In the future, asking interview questions in a different order during each consultation may account for this. The specific regions in which the men reside were not take into consideration. It is possible that men who live in larger cities with access to sexual rehabilitation programs would have differing viewpoints from men living in areas where sexual rehabilitation resources are not readily available.

Possible limitations regarding the Delphi studies also existed. Panel members were purposefully selected based on their expertise and knowledge on the topic, and because the sample was not selected randomly, the panel was not guaranteed to be representative of the larger population (Hasson et al., 2000). Additionally, as a result of snowball sampling, the group of men who completed the Delphi survey included a large number of high-performing para-athletes. Athletes may have increased confidence as a result of their athletic accomplishments, may have fewer body issues as a result of being physically active and may also adhere to masculinity norms which may all affect the types of responses that were obtained. Participants were self-selected, and the sample of healthcare providers may bear some bias based on the type of healthcare provider who would choose to participate in a study on sexuality. Future research should consider the healthcare provider's interest in sexual rehabilitation and motivation for participating.

Encouraging the men to be open and honest during qualitative interviews required a great deal of effort on the part of the researcher. The Delphi surveys were completed online, and the men were left to their own devices when answering the questions. The researcher wonders if the men would be able to achieve the same level of openness when answering questions on their own, and must consider if the Delphi responses were unintentionally untruthful as a result of answering within their comfort zone.

Healthcare provider responses may have been informed by experience and/or previous evidence, however, it is also possible that their responses were drawn from their own personal beliefs. In that case, responses may reflect healthcare providers' own thoughts of what it would be like for them if they had a

SCI and what they *think* they would want if they had a disability rather than on best available evidence or patient experiences. In the case of the latter, healthcare provider responses may be influenced by societal perceptions of body image, masculinity, sexuality and disability. Without lived experience, one should base their recommendations on best available evidence, listen to the perspectives of men who live with a SCI and explore each individual's experience when developing a sexual health plan for patients.

Though many items in the Delphi surveys reached a consensus, it does not necessarily mean that the correct answers have been identified, only that an agreement on items was reached for this panel of experts (Hasson et al., 2000).

The majority of participants with SCI in both the phenomenological and Delphi studies had participated in sexual activities post-SCI. Individuals who had not participated in sexual activities may have felt that they could not contribute to the research (Anderson et al., 2007). Therefore, it is possible that the important reasons some individuals avoid sexual activities post-injury were missed.

Future Directions

During the phenomenological interviews, men touched on the topic of dating with a SCI. They discussed physical challenges pertaining to the limited accessibility of establishments within society that lead to decreased access to social activities and decreased opportunities to meet a new potential partner. Men also discussed concerns regarding the accessibility of venues when going on a date, as well as concerns about the accessibility of public restroom facilities. Furthermore, the challenges of online dating as a man with SCI were discussed. Future research should consider the dating experience for men with SCI to identify potential challenges and offer suggestions and strategies.

Conclusions

Despite consistently being reported as highly important, sexuality for men after SCI has been largely overlooked and underexplored. We must raise awareness regarding the continued need for intimate and sexual relationships after SCI, and normalize a person's desire to receive sexual health education, and to participate in sexual activities post-injury (Consortium for Spinal Cord Medicine, 2010).

Canadian sexual health models are inadequate in meeting the broad scope of sexual health requirements of men living with SCI (Craven et al., 2012). Consideration of psychosocial and emotional aspects of sexuality, modification of self-view and societal-view, restoration of confidence and self-esteem, rewriting the harmful misconceptions of society, and addressing the current lack of information and awareness are vital to enhancing the sexual experience of men after SCI. Policies should be put in place to advocate the clinical importance of supporting sexual health (Pieters et al., 2018), and healthcare providers from various disciplines should be willing to start conversations about sexuality and include sexual health as an integral component of rehabilitation (Elliott et al., 1997).

Elliott and colleagues (2019) identified the creation of a permissive environment amid healthcare providers regarding sexual health as the driver most likely to advance SCI rehabilitation in the near future. The importance of the healthcare provider in the sexual adjustment of men after SCI was made evident throughout the series of studies which comprise this dissertation. As researchers, clinicians and health care providers, we should also be open to expanding our views of sex and sexuality when working with this patient population. Traditional sexual health information should be provided, but we should also be open to considering and discussing other ways in which individuals living with SCI may be able to explore and experience sexuality. Finding a balance between this type of open conversation while respecting the comfort of both the patient and healthcare provider should be explored. Healthcare providers in the position of discussing revolutionary sexual activities should be aware of their own biases and be prepared to suspend any judgements to facilitate a safe and productive discussion about sex after SCI.

To correct the disconnect in areas where healthcare provider perceptions and understanding are misaligned with patient experiences resulting in disparities in care, future efforts should focus on areas where healthcare provider responses were not aligned with patient responses. Healthcare providers should be made aware of the evolved meaning of sexuality for men with SCI forthwith as they cannot provide adequate support if they do not know what the patient requires. Tools and resources should be developed in conjunction with input from those living with SCI (Elliott et al., 2019; New, 2018; Pieters et al., 2018) and best-practice guidelines should be co-created with patient input, as well as with consideration of existing literature.

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APPENDICES

Appendix A: *Research Ethics Approval- York University (Study one)*

YORK
UNIVERSITÉ
UNIVERSITY

OFFICE OF
RESEARCH
ETHICS (ORE)
5th Floor, Kaneff
Tower

4700 Keele St.
Toronto ON
Canada M3J 1P3
Tel 416 736 5914
Fax 416 736-5512
www.research.yorku.ca

Certificate #:	**STU 2018 - 050**
Approval Period:	**05/17/18-05/17/19**

ETHICS APPROVAL

To: **Jacqueline Cramp**
Graduate Student of Kinesiology & Health Science, Faculty of Health
crampj@yorku.ca

From: Alison M. Collins-Mrakas, Sr. Manager and Policy Advisor, Research Ethics
(on behalf of Veronica Jamnik, Chair, Human Participants Review Committee)

Date: Thursday, May 17, 2018

Title: **Examining the Psychological and Emotional Experience of Sexuality for Men with Spinal Cord Injury**

Risk Level: ☒ Minimal Risk ☐ More than Minimal Risk

Level of Review: ☒ Delegated Review ☐ Full Committee Review

I am writing to inform you that this research project, **"Examining the Psychological and Emotional Experience of Sexuality for Men with Spinal Cord Injury"** has received ethics review and approval by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines.

Note that approval is granted for one year. Ongoing research – research that extends beyond one year – must be renewed prior to the expiry date.

Any changes to the approved protocol must be reviewed and approved through the amendment process by submission of an amendment application to the HPRC prior to its implementation.

Any adverse or unanticipated events in the research should be reported to the Office of Research ethics (ore@yorku.ca) as soon as possible.

For further information on researcher responsibilities as it pertains to this approved research ethics protocol, please refer to the attached document, **"RESEARCH ETHICS: PROCEDURES to ENSURE ONGOING COMPLIANCE".**

Should you have any questions, please feel free to contact me at: 416-736-5914 or via email at: acollins@yorku.ca.

Yours sincerely,

Alison M. Collins-Mrakas M.Sc., LLM
Sr. Manager and Policy Advisor,
Office of Research Ethics

Appendix B: *Research Ethics Approval- Brock University (Study one)*

Brock University
Research Ethics Office
Tel: 905-688-5550 ext. 3035
Email: reb@brocku.ca

Bioscience Research Ethics Board

Certificate of Ethics Clearance for Human Participant Research

DATE:	5/23/2018		
PRINCIPAL INVESTIGATOR:	GAGE, William - Kinesiology		
CO-INVESTIGATOR(S):	David Ditor (dditor@brocku.ca)		
FILE:	17-403 - GAGE		
TYPE:	Ph. D.	STUDENT:	Jackie Cramp
		SUPERVISOR:	William Gage

TITLE: Examining the Psychological and Emotional Experience of Sexuality for Men with Spinal Cord Injury

ETHICS CLEARANCE GRANTED

Type of Clearance: NEW Expiry Date: 5/1/2019

The Brock University Bioscience Research Ethics Board has reviewed the above named research proposal and considers the procedures, as described by the applicant, to conform to the University's ethical standards and the Tri-Council Policy Statement. Clearance granted from **5/23/2018** to **5/1/2019**.

The Tri-Council Policy Statement requires that ongoing research be monitored by, at a minimum, an annual report. Should your project extend beyond the expiry date, you are required to submit a Renewal form before 5/1/2019. Continued clearance is contingent on timely submission of reports.

To comply with the Tri-Council Policy Statement, you must also submit a final report upon completion of your project. All report forms can be found on the Research Ethics web page at http://www.brocku.ca/research/policies-and-forms/research-forms

In addition, throughout your research, you must report promptly to the REB:

a) Changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
b) All adverse and/or unanticipated experiences or events that may have real or potential unfavourable implications for participants;
c) New information that may adversely affect the safety of the participants or the conduct of the study;
d) Any changes in your source of funding or new funding to a previously unfunded project.

We wish you success with your research.

Approved: 

Stephen Cheung, Chair
Bioscience Research Ethics Board

Note: Brock University is accountable for the research carried out in its own jurisdiction or under its auspices and may refuse certain research even though the REB has found it ethically acceptable.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and clearance of those facilities or institutions are obtained and filed with the REB prior to the initiation of research at that site.

Appendix C: ***Participant Information and Consent Form (Study one)***

Letter of Invitation and Consent Form

Utilizing a Phenomenological Approach to Examine the Experience of Sexuality Among Men After Spinal Cord Injury

Please consider this an invitation to voluntarily participate in a research investigation examining the experience of sexuality among men with spinal cord injury. This study will be directed by Dr. Will Gage in the Department of Kinesiology and Applied Health Science at York University. In this letter, you will find a detailed description of the study that will assist you in your decision to either participate, or not participate in this study. Please take a minute to carefully read through this letter. Do not hesitate to ask for clarification, or to ask any questions you may have regarding either this letter or the study. Should you require further information, please contact the principle student investigator or the faculty supervisor using the contact information provided below.

Principle Student Investigator: Jackie Cramp, PhD Graduate Student, Department of Kinesiology and Applied Health Sciences, York University; crampj@yorku.ca
Faculty Supervisor: Dr. Will Gage, Professor, Department of Kinesiology and Applied Health Science, York University; whgage@yorku.ca

This study has been approved by the York University Research Ethics Board (File number 2018-050) and the Brock University Research Ethics Board (File number 17-403) and conforms to research ethics protocols by the Human Participants Review Subcommittee (HPRC) of York University and TCPS2. Should you require further information regarding the ethical approval of this study, or about your rights as a participant in this study, please contact the Sr. Manager & Policy Advisor for the Office of Research Ethics, 5th Floor, Kaneff Tower, York University (telephone 416-736-5914 or e-mail ore@yorku.ca) or Manager, Office of Research Ethics, York University, 309 York Lanes, phone 416-736-5914.

PURPOSE OF THE STUDY

The purpose of this study is to examine the lived emotional and psychological experiences of sexuality among men with spinal cord injury. The hope is that by exploring this often overlooked phenomenon we will be able to uncover the related concerns with the highest priorities for this population and direct future research towards to these identified areas.

STUDY PROCEDURES

Should you choose to participate in this study, you will be required to complete a 1 – 1.5 hour interview with the researcher. The interview will take place either by telephone call or in-person interview. The interview will be audio recorded and transcribed verbatim. Only one interview is required and it will focus on your own experiences regarding the effects of spinal cord injury on sexuality. The interview is an excellent opportunity for you to share your story, your knowledge and your concerns.

POTENTIAL RISKS

Discussing experiences of a personal nature may create some feelings of trepidation emotional stress. Please keep in mind that you will be able to avoid answering any questions that make you feel uncomfortable. Contact information for relevant organizations will be provided to you should you require support. Furthermore, the researcher has participated in a formal phenomenological interviewer training and is prepared to manage these risks.

POTENTIAL BENEFITS

Potential benefits of participating in this study include the opportunity to discuss your experiences regarding this very important topic. You will have the opportunity to see a description of the meaning pertaining to your own experiences, and to consider your experiences in relation to those of other men with spinal cord injury. The information revealed during this investigation may have the ability to guide future research and/or practice to ensure that the areas being targeted by researchers and health care providers represent the main concerns of the men they aim to help.

COMPENSATION
There will be no financial compensation for participation in this study.

CONFIDENTIALITY
The information you provide will be kept confidential. Your name will not appear in any thesis or report resulting from this study; however, with your permission, a pseudonym and anonymous quotations may be used. Shortly after the interview has been completed, you can request a copy of the transcript if you would like an opportunity to confirm the accuracy of our conversation and to add or clarify any points.

VOLUNTARY PARTICIPATION
Participation in this study is strictly voluntary and the choice whether or not to participate is up to you. You have the right to forfeit answering any question(s) you choose while still remaining in the study, as well as the right to withdraw from the study at any time without penalty. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with the researchers, York University, or any other group associated with this project. In the event that you withdraw from the study, all associated data collected will be immediately destroyed wherever possible.

ACCESSING FINDINGS OF THIS STUDY/ PUBLICATION OF RESULTS
Results of this study may be published in professional journals and presented at conferences. You will also have the option to receive a full copy of the completed paper, as per your request.

CONSENT FORM
I agree to be audio recorded Yes □ No □
I agree to participate in the study described above and I have made this decision voluntarily based on the information provided in the Information-Consent Letter. The study has been explained to me and any questions I that I had have all been answered to my contentment. I understand that I may ask additional questions in the future, and that I maintain the right to withdraw this consent at any time.

Participant Name (please print): _____

Signature:_____Date:_____

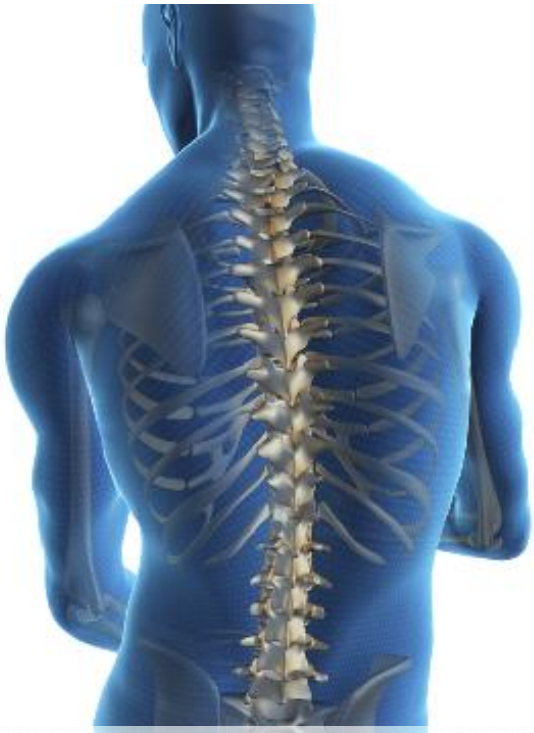
Witness Name (please print): _____

Signature: _____Date: _____

Appendix D: ***Recruitment Poster (Study one)***

SEXUALITY AMONG MEN WITH SPINAL CORD INJURY

Participants needed!



We are looking for **men 18 - 50 years of age** who have a **spinal cord injury** to participate in a confidential, 60-90 minute interview which will focus on the psychological and emotional impact of spinal cord injury on sexuality.

If you are interested in participating, please contact Jackie Cramp, PhD Candidate, Faculty of Kinesiology and Applied Health Science, York University at crampj@yorku.ca.

YORK UNIVERSITÉ UNIVERSITY

Ethics Clearance File Number 2018-050 & 17-403

SCI study crampj@yorku.ca

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Appendix E: ***Interview Guide (Study one)***

Hello and thank you for speaking with me today.

This study involves a demographic questionnaire and a 1 to 1.5 hour in-depth interview. During the interview, we will be discussing sexuality after spinal cord injury. As we talk about sexuality and sexual function, I want you to know that when I use these terms I am referring to anything from the emotional intimacy experienced with a partner to the actual act of sexual intercourse, and everything in between unless specified otherwise.

Your interview will be audio recorded and transcribed verbatim. The audio recording will be used during the analysis process. I will also be taking some notes during the interview to record any information that stands out to me, or topics that I may want to come back to later in the interview. You may look over these notes at the end of the interview if you request to do so.

There are no right or wrong answers to any of the questions that I ask you today. I am here to learn about your own personal thoughts and experiences. During the interview, you may choose not to answer any question(s) that make you uncomfortable, or to terminate your interview at any time for any reason with no consequences whatsoever. I have provided some resources in your information-consent letter of organizations that you can contact should our discussion today evoke any feelings of distress. The information you provide will be kept confidential, and we will be using a pseudonym from this point forward to protect your identity. Can you please think of a name other than your own that you would like to be referred to throughout the remainder of this study?

Do you have any other questions before we begin the interview?

Phenomenological Question: What is the experience of sexuality for men after spinal cord injury?

Interview Questions:

1. Can you start by telling me a little bit about yourself and your spinal cord injury?
   (Demographic/Background Question)
   Probe questions:
   a. How would you describe yourself (personality, character, interests…)?
   b. Can you tell me a little bit about your injury (level, classification, circumstances, interpretation of impact on life, generally…)?
   c. Tell me about your current relationship status (if separated/ divorced what do you think caused the relationship to end? If single is that by preference? Why do you think you are single? If in a relationship that started prior to the injury how has the relationship changed since the injury)?
   d. Prior to your injury, did you see yourself as a married person with children? And now?
   e. What challenges do you face when establishing new relationships, both in friendship and romantic contexts?
   f. How is, or how do you think, dating is different for someone with a SCI? (methods of meeting/dating, additional complications/ challenges, qualities you look for in a partner before/ after injury)?

2. What is the meaning of sexuality to you?
   (Opinion/Value Question)

Probe Questions:

a. How is the meaning of sexuality different before versus after your injury?
b. How did your SCI change or expand what sexuality means to you?
c. What experiences led to these beliefs (both before and after SCI)? (society?)
d. What role does sexuality play in your life?

3. How has your spinal cord injury impacted your sexuality and/or sexual function?
(Experience/Behavior Question)
Probe Questions:
    a. Did you participate in sexual activities prior to your injury (the term 'sexual activities' refers to a broad range of activities and does not necessarily mean sexual intercourse)?
        > Any sexual challenges prior to SCI (meaning **not** related to SCI; examples: medical comorbidity, sexual abuse, emotional issues, performance related issues)
        > Can we talk about what was going on at that time?
        (Sexual history assessment questions to separate challenges resulting from SCI from those not related to SCI)
    b. Have you participated in sexual activities since your injury?
        > What types of sexual activities? How do these activities differ from the activities you preferred prior to your injury?
        > More emphasis on psychological/ emotional factors? Closeness?
        > How long after SCI before you began participating in sexual activities?
    Why?
    c. Has your desire or interest in sexuality changed since the injury?
    d. Have there been changes in erection (obtaining, sustaining)?
    e. Have there been changes in your ability to reach orgasm?
    f. How have any of the changes described affected your sexual life? (ex. increased/ decreased creativity/sexual exploration, development of new erogenous zones, use of sexual aids: oral medications, topical agents, injections, devices, implants, etc)

4. Describe a time, after SCI, when you felt sexually satisfied (or describe a situation that would make you feel sexually satisfied)
(Opinion/Value Question)
Probe Questions:
    a. What made it satisfying for you?
    a. Under what conditions would you consider yourself sexually satisfied? (physical? emotional? psychological?)
    b. How satisfied are you with your sexual life?

5. How would you describe any body issues that you are concerned about when participating in, or thinking about participating in sexual activities?
(Sensory Question)
Probe Questions:
    a. What changes regarding your body have affected your sexual life? (ie: body image, bladder, bowel, spasticity, pain, fatigue, decreased mobility, decreased sensation, skin issues, autonomic dysreflexia…)

b. To what extent are these issues a concern for you?
c. To what extent does your fear of these body issues affect your sexuality?
d. What about preparation for sexual activities? What precautions do you take prior to engaging in sexual activities to account for these issues/ concerns?
e. How does it make you feel when you have to discuss these concerns with your partner? How does this affect the sexual experience?
f. How are the concerns you have similar or different to the concerns of your partner(s)?
g. How much disclosure do you feel is appropriate when discussing sex after SCI with a new potential partner?

6. How has your spinal cord injury affected the way you see yourself? How has this affected your sexuality?
(Opinion/Value Question)
Probe Questions:
   a. How has your SCI affected your self-esteem? Body-esteem? Body image? Sexual confidence? Self confidence?
   b. How do you feel about, or how have you been affected by the societal obsession with 'ideal bodies?' (social pressures, attractiveness, non-typical bodies)
   c. How do you think this is different for women with SCI than it is for men with SCI?

7. Tell me a story about a time or situation when your SCI affected your sexual life.
(Opinion/Value Question)
Probe Questions:
   a. Positive or negative experience?
   b. Describe the worst possible case scenario that has either happened, or could happen to you related to sex after SCI.
   c. Describe the best possible case scenario that has either happened, or could happen to you related to sex after SCI.

8. As you talk about and reflect on your sexual life after spinal cord injury, what types of feelings and emotions are you experiencing?
(Feeling/Emotion Question)
Probe Questions:
   e. Frustration? Disappointment? Sadness? Longing? Pride? Amazement?
   f. What types of feelings and emotions have you experienced in your sexual relationships?

9. What resources have you used or accessed (books, pamphlets, videos, support groups) to help with sexual adjustment (sexuality, sexual function) after SCI?
(Knowledge Question)
Probe Questions:
   a. How useful are these resources?
   b. Where did you get them?
   c. When did you access them?
   d. How much information was provided to you regarding sexuality after SCI after your injury?
   e. What was your initial reaction to this information?

f. What resources are you aware of that you have not used or accessed?
g. Is the amount of information that is available adequate? What is missing?
h. How much would you say these resources are targeted towards men? Women?
i. Do you think there is an optimal time to begin talking about sexuality?
j. Who would be the ideal person to talk to you about sexual issues after SCI (health care professional, peer, male, female, SCI, able-bodied)?
k. To what extent are your Doctors/ health care providers comfortable discussing sexual function with you?
l. How comfortable were you asking health care providers questions about your sexual functioning/ interventions to help with sexual functioning?
> What were some of the barriers to this conversation?
> What were some of the facilitators to this conversation?
m. To what extent are your Doctors/ health care providers knowledgeable on the topic of male sexual function after SCI?
n. Do you think there is a health profession that is more suited than others to address this?

10. Is there anything that we didn't talk about today that you would like to discuss now, or is there anything that you would like to add to our conversation?
(Final Question)

Appendix F: ***Additional Participant Revelatory Quotes***

Additional Revelatory Quotes

Steve: *"…to find out whether or not I could physically ejaculate they did vibrostim and that was the most horrible experience ever because I have hyperreflexia, so pressure shoots through the roof. Something that was pleasurable before is now causing you horrible discomfort and danger… So there's this doctor and five nurses by the table and they're all there. And I'm thinking in my head, are they going to have a catcher's mitt or something? (laughs). So the doctor does his little vibrostim and my blood pressure's shooting through the roof. And it's crazy, like 220 over 160 and they're giving you medication and they're monitoring saying 'are you okay.' And then the big even happens, 'what the hell happened?' 'you ejaculated a little bit.' I'm like, 'okay is there anything there?' and the guy lets me check in the microscope and the 55 to 60-year-old nurse standing beside me goes 'do you want a cigarette?' (laughs) …And I'm like 'Oh my god, this is hilarious.' Like that whole experience, it sucked… But when I first got injured, there wasn't even that vibrostim thing, they actually put electrodes up your butt to make you ejaculate. And my friend went through it and he was like devastated. Cuz the electrodes, he's like 'I don't know why they made the electrodes look like this' he goes 'it looked like the biggest wackiest dildo you've seen shoved up my butt'. I'm like 'oh well that's great, something to look forward to'. So, you know that was a big impact."*

Will: *"An ex-girlfriend of mine actually came to visit me [in the hospital after SCI]… I can remember specifically reaching down just to touch myself and coming to the shock that I really couldn't tell all that much what I was doing when I was doing that. And uhh, that was my first indication that there was going to be problems going forward… But it's something that to this day still, is clear in my head as a significant event… It was a fight…trying to convince myself that 'no, it wasn't true'. Umm, that no I could still be 'normal' quote unquote.*

Elliott: *"The worst possible was when my high school girlfriend and I wanted to go on a trip to Kingston, and at that point I wasn't hiring my own attendants so we had to travel with my parents… and my parents had to rent a separate hotel [room]. And this is probably a year after my spinal cord injury. So everything was still very, very fresh, and my parents were helping me transfer into bed and it turned out that I guess my bowel routine that previous morning wasn't effective, and I had major explosions of my bowels, and so not only was my girlfriend in the room at the time, both of my parents were there, and so my parents have to deal with it, which is a nightmare to begin with and then that just basically put a stop to anything [sexual] happening between my girlfriend and I that night. Because I wasn't interested in anything happening, because I just felt disgusting… and unfortunately not too long after that, my relationship with my high school girlfriend ended."*
Interviewer: *"After that experience, was that something that you were concerned about in future sexual activity for a while afterwards?"*
Elliott: *"Yeah, definitely. The evening before anyone would come over, I would stop taking really important bowel medication that I needed to go to the bathroom. So if I were to have someone come over and if they'd sleep over that's fine, but I couldn't go to the bathroom for the next two days because I would just basically try to make myself as constipated as possible."*
Interviewer: *"Did it ever prevent you from participating in sexual activity, or going after a certain sexual experience, because you were concerned about it?"*
Elliott: *"Yeah, it definitely has. And probably the [place where it affected me most] was on my honeymoon. [Because of] the time change, my body was just not cooperating. And so on my honeymoon in Paris I just was like I don't know if my bowels will cooperate and so my entire honeymoon we didn't do anything [sexually] because I was like 'I don't want anything [bowel incontinence] to happen' and yeah it was a bit of a nightmare. Yeah, so it definitely… affected me there."*

Joe: *"The only time I've had that happen [someone run away] was on Tinder (laughing), and I was talking to this girl for two weeks and we were getting along great. And right on my profile there's a picture of me in a wheelchair, my photos are of me in a wheelchair, and all of a sudden, I said something about physiotherapy and she goes 'why are you in physiotherapy?' And I said 'well because of my injury,' and obviously she went back and read my profile and she just disappeared completely. Unmatched. Gone. (laughs)… At first it was frustrating because like, the picture is on my page. It sounded like I met someone that had a future, but then I realized after that that she just saved me a ton of time and emotional investment in a relationship, and if she's that shallow then it kind of saved me the effort, right? …Some people aren't really comfortable with it, and you have to kind of accept that."*

Paul: *"I just find it very hard with the disability trying to meet somebody that my injury will work for them, so to speak…I go through explaining my whole situation to somebody as they ask questions. I explain around, and then the next thing you know they disappear…It just got to be a whole lot of work that just didn't seem to be worth it… for no returns. It's frustrating and I want to give up sometimes. Not even bother…But I don't get upset about it. I get it, you know? This is not for everybody. And I always look at it if it was the other way around, it may not be my cup of tea either. So I totally understand that, but yeah it's difficult..."*

Steve: *"I kind of let her go. I kind of said 'it's okay. You're young, I'm young, you need to move on,' and just ended it that way and that was it. I just didn't want her to feel that she needed to stay in with me because of what happened… It was just me kind of saying you know 'don't feel bad.' Like, I didn't want her to feel bad the rest of her life, 'oh I should have stayed with him so he could…' that kind of thing. So I just kind of said 'it's okay, you know just leave it'.*

Peter: *"So I try to ease the load so it's not, you know, overly burdened on my wife. Because I know it is a lot of, you know, you basically have to spend like 90% of your time looking after somebody else… can see that would be tiring. And it takes a toll, right?"*

Paul: *"There is a possibility of having involuntary bowel movements. So that's a huge concern. And that's probably one of my major, major concerns of getting close to somebody, or getting intimate with somebody. That, if you had an accident or something, that would devastate me more than anything that's ever happened to me, so that holds me back a lot too. It's not something that happens, but it's a possibility, and you know, I always think to myself 'what could go wrong, will go wrong.' So I worry about it constantly."*

Interviewer: *"How did that conversation [about bowel issues] go?"*
Paul: *"I'm not sure people really know how to respond to it."*
Interviewer: *"Was it a conversation that you were nervous to have?"*
Paul: *"Oh yes, absolutely. I started to wear Depends, just when I'm outside, so I could be comfortable and not worry about it [urinary incontinence]. …I continued to wear them for the fact of worrying about an accidental bowel movement, and I still wear them now. So that's another thing I got to bring up to a potential partner. You know, I joke about it with my friends and say they're what I call my 'not-so-sexy-underwear' (laughs)… So that's another issue that comes up that I have to talk about. And that one terrifies me a lot too because, you know, I don't know what people's thoughts are on that. It's many years before I expected to be wearing them (laughs)."*

Joe: *"At the beginning I wasn't comfortable at all with it [discussing sex after SCI]. I would find myself very careful with my words…like you don't want to give too much information… But now I find it super important to make sure that they know [about the possibility of incontinence and spasticity during sexual activity]. You never want to catch someone off guard with something like that… or if I didn't have a*

wheelchair on my [dating] profile and I show up to the date sitting in a wheelchair, like a blind date, that's not cool at all. So, I think providing the information that they need to know is most important."

Paul: *"We started the divorce a year after [my SCI]. I got hit by a surprise divorce which was another blow. I just got back on my feet again, so to speak, and then I got hit with that. So that was a bit devastating. A lot of people ask me, and I think the answer is it was gonna happen regardless of my injury. Umm… but I think it [the SCI] was also the straw that broke the camel's back so to speak."*

Elliott: *"I've got a number of positive stories that I could obviously share, but I think the ones that really stick out for me are the ones that might be negative. For example, when I was just starting to [be intimate with] someone, the first tricky part was negotiating whether or not this person wanted my attendants to help transfer me into bed at night, and I always ask all of my sexual partners before-hand what they're comfortable with and what they're not comfortable with. So that was the first issue. The first official sleepover night when we're going to come home and she is going to stay the night… so for a lot of people this is probably a very important night in the relationship. And so just planning for it was obviously chaotic because I had to figure out if she wanted anyone [attendants] to stay. And she didn't want anyone to stay the night and that was fine, and she was comfortable with the transferring [into bed] and stuff like that. Then we started the usual foreplay, like whether it's kissing or whatever, in bed. And then it came time to try and trigger a reflex erection, and it just was not cooperating. It just wasn't happening, and it's just like, 'well this is not great.' So we end up skipping that and I started some other sexual activities on her to try and make her comfortable or enjoy the moment as much as possible. And I thought that I had done a good job. In the morning, all of sudden, surprisingly, we finally triggered an erection and that was great. But actually, after that whole experience, and just realizing that life can't be as spontaneous as possible, she said, 'I'm okay with keeping this relationship open, but I don't really want to maintain a sense of close relationship.' And so that obviously sunk into my head because that was a bit of a big failure for me, which is something that is probably going to happen to anyone, but especially having a spinal cord injury. I think that one definitely stands out to me."*
Interviewer: *"And how did that impact you moving forward in other relationships?"*
Elliott: *"I think I would just always think about that night when basically the next morning she just said, 'you know, I don't think that spark is there anymore,' and she didn't necessarily specifically say why it wasn't there, but I was pretty quick to understand why it wasn't there anymore after everything that had transpired. And the way it affected me is I think I just constantly thought about it in all of my future relationships. It's like, 'oh is this going to end tomorrow morning?' It came up in my mind quite a lot."*

Appendix G: ***Research Ethics Approval- York University (Studies two and three)***

YORK
UNIVERSITÉ
UNIVERSITY

OFFICE OF RESEARCH ETHICS (ORE)
5th Floor, Kaneff Tower

4700 Keele St.
Toronto ON
Canada M3J 1P3
Tel 416 736 5914
Fax 416 736-5512
www.research.yorku.ca

Certificate #:	**STU 2019-004**
Approval Period:	**01/31/19-01/31/20**

ETHICS APPROVAL

To: **Jacqueline Kathnelson**
School of Kinesiology and Health Sciences
Graduate Program
Crampj@yorku.ca

From: Alison M. Collins-Mrakas, Sr. Manager and Policy Advisor, Research Ethics
(on behalf of Denise Henriques, Chair, Human Participants Review Committee)

Date: Thursday January 31, 2019

Title: **Utilizing The Delphi Method to Identify the Most Important Psychological and Emotional Concerns Regarding Sexuality for Men After Spinal Cord Inqury from Both the Patient and Health Care Provider Perspective**

Risk Level: ☒ Minimal Risk ☐ More than Minimal Risk

Level of Review: ☒ Delegated Review ☐ Full Committee Review

I am writing to inform you that this research project, **"Utilizing The Delphi Method to Identify the Most Important Psychological and Emotional Concerns Regarding Sexuality for Men After Spinal Cord Inqury from Both the Patient and Health Care Provider Perspective"** has received ethics review and approval by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines.

Note that approval is granted for one year. Ongoing research – research that extends beyond one year – must be renewed prior to the expiry date.

Any changes to the approved protocol must be reviewed and approved through the amendment process by submission of an amendment application to the HPRC prior to its implementation.

Any adverse or unanticipated events in the research should be reported to the Office of Research ethics (ore@yorku.ca) as soon as possible.

For further information on researcher responsibilities as it pertains to this approved research ethics protocol, please refer to the attached document, **"RESEARCH ETHICS: PROCEDURES to ENSURE ONGOING COMPLIANCE".**

Should you have any questions, please feel free to contact me at: 416-736-5914 or via email at: acollins@yorku.ca.

Yours sincerely,

Alison M. Collins-Mrakas M.Sc., LLM
Sr. Manager and Policy Advisor,

Appendix H: *Research Ethics Approval- Brock University (Studies two and three)*

Brock University
Research Ethics Office
Tel: 905-688-5550 ext. 3035
Email: reb@brocku.ca

Social Science Research Ethics Board

Certificate of Ethics Clearance for Human Participant Research

DATE: 2/21/2019

PRINCIPAL INVESTIGATOR: GAGE, William - Kinesiology

FILE: 18-235 - GAGE

TYPE: Ph. D. Supervisor: David Ditor
Brock Researcher: David Ditor

TITLE: Utilizing the Delphi Method to Identify the Most Important Psychological and Emotional Concerns Regarding Sexuality for Men after Spinal Cord Injury from both the Patient and Health Care Provider Perspective

ETHICS CLEARANCE GRANTED

Type of Clearance: NEW Expiry Date: 2/1/2020

The Brock University Social Science Research Ethics Board has reviewed the above named research proposal and considers the procedures, as described by the applicant, to conform to the University's ethical standards and the Tri-Council Policy Statement. Clearance granted from **2/21/2019 to 2/1/2020**.

The Tri-Council Policy Statement requires that ongoing research be monitored by, at a minimum, an annual report. Should your project extend beyond the expiry date, you are required to submit a Renewal form before **2/1/2020**. Continued clearance is contingent on timely submission of reports.

To comply with the Tri-Council Policy Statement, you must also submit a final report upon completion of your project. All report forms can be found on the Research Ethics web page at http://www.brocku.ca/research/policies-and-forms/research-forms

In addition, throughout your research, you must report promptly to the REB:

a) Changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
b) All adverse and/or unanticipated experiences or events that may have real or potential unfavourable implications for participants;
c) New information that may adversely affect the safety of the participants or the conduct of the study;
d) Any changes in your source of funding or new funding to a previously unfunded project.

We wish you success with your research.

Approved:

Lynn Dempsey, Chair
Social Science Research Ethics Board

Robert Steinbauer, Chair
Social Science Research Ethics Board

Note: Brock University is accountable for the research carried out in its own jurisdiction or under its auspices and may refuse certain research even though the REB has found it ethically acceptable.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and clearance of those facilities or institutions are obtained and filed with the REB prior to the initiation of research at that site.

Appendix I: ***Recruitment Poster- Men with SCI (Study two)***

SEXUALITY AMONG MEN WITH SPINAL CORD INJURY

Participants needed!

Receive a $10 gift card!
We are looking for **men**
18 years and older who have a **spinal cord injury** to participate in a series of three confidential, **15-20 minute** online surveys focusing on the psychological concerns of sexuality after spinal cord injury.

If you are interested in participating, please contact Jackie Kathnelson, PhD Candidate, School of Kinesiology and Health Science,
York University at crampj@yorku.ca

YORK UNIVERSITÉ UNIVERSITY

This file has been reviewed and received ethics clearance from the York University Research Ethics Board (2019-004) 416-736-5914; ore@yorku.ca and the Brock University Research Ethics Board (18-235) 905-688-5550 Ext. 3035; reb@brocku.ca

SCI study crampj@yorku.ca SCI study crampj@yorku.ca SCI study crampj@yorku.ca SCI study crampj@yorku.ca SCI study crampj@yorku.ca SCI study crampj@yorku.ca SCI study crampj@yorku.ca SCI study crampj@yorku.ca SCI study crampj@yorku.ca SCI study crampj@yorku.ca

Appendix J: ***Participant Information Letter (Study two)***

Letter of Invitation

Using the Delphi Method to Identify Top Psychological and Emotional Concerns of Sexuality Among Men After Spinal Cord Injury

Please consider this an invitation to voluntarily participate in a research investigation examining the psychological and emotional concerns of sexuality among men with spinal cord injury. This study will be directed by Dr. William Gage in the School of Kinesiology and Health Science at York University. In this letter, you will find a detailed description of the study that will assist you in your decision to either participate, or not participate in this study. Please take a minute to carefully read through this letter. Do not hesitate to ask for clarification, or to ask any questions you may have regarding either this letter or the study. Should you require further information, please contact the principle student investigator or the faculty supervisor using the contact information provided below.

Principle Student Investigator: Jackie Kathnelson, PhD Candidate, School of Kinesiology and Health Science, York University; crampj@yorku.ca
Faculty Supervisor: Dr. William Gage, Professor, School of Kinesiology and Health Science, York University; whgage@yorku.ca

This study has received clearance from the York University Research Ethics Board (File number 2019-004) and the Brock University Research Ethics Board (File number 18- 235) and conforms to research ethics protocols by the Human Participants Review Subcommittee (HPRC) of York University and TCPS2. Should you require further information regarding the ethical approval of this study, or about your rights as a participant in this study, please contact the Sr. Manager & Policy Advisor for the Office of Research Ethics, 5th Floor, Kaneff Tower, York University (telephone 416-736-5914 or e-mail ore@yorku.ca) or Manager, Office of Research Ethics, York University, 309 York Lanes, phone 416-736-5914. You may also contact the Research Ethics Officer at Brock University (telephone 905-688-5550 ext. 3035 or e-mail reb@brocku.ca).

PURPOSE OF THE STUDY

The purpose of this study is to identify and verify the most important psychological and emotional concerns regarding sexuality among men with spinal cord injury. Using the Delphi Method, our aim is to generate a level of agreement regarding the importance of these issues based on the opinions of our expert panelists. Once we have determined the concerns ranked highest in priority for this population, we can direct future research towards to these identified areas.

WHY HAVE YOU BEEN CHOSEN?

You have been chosen to participate in this study as an expert panelist because you have been identified as having an important perspective and relevant expertise in this topic. Your opinion is valuable to the research investigation.

STUDY PROCEDURES

Should you choose to participate in this study, you will be asked to complete a Delphi exercise involving a 15-20 minute online survey on three separate occasions. You will be asked to complete and submit each survey within one week. In round one, you will be asked to provide responses and ratings to a series of questions. Once we receive all responses from all expert panelists, we will collate and summarize the findings, and based on the comments provided and answers given, we will formulate the round two survey. In round two, you will again be asked to rate a series of questions. In round three, you will receive information about the average responses of other panelists, and with that information, you will be given the opportunity to revise your answers. It is important that you complete all three rounds. The aim is for the Delphi exercise to build understanding and consensus around the top priorities.

POTENTIAL RISKS

Answering questions of a personal nature may produce some feelings of emotional stress including sadness, anger or embarrassment. Please keep in mind that you can choose not to answer any question(s) that make you feel uncomfortable. If you feel that you have been affected by any of the questions in this study, please access the link below for external support.

https://sciontario.org/contact-us/

POTENTIAL BENEFITS

Potential benefits of participating in this study include the opportunity to reflect on your own feelings regarding this very important topic and having the opportunity to consider your top psychological and emotional concerns regarding sexuality after spinal cord injury in relation to those of other men with spinal cord injury. The information collected during this investigation may have the ability to guide future research and/or best-practice guidelines to ensure the areas being targeted by researchers and health care providers represent the main concerns of the men they aim to help.

COMPENSATION

As a thank you for your time, participants will receive a $10 Tim Hortons gift card after completing the surveys. The gift card will be sent to your email address.

CONFIDENTIALITY

The information you provide and your individual responses will be kept confidential. All data will be stored securely and will be accessible only by the Principal Student Investigator. Other panelists will not be able to see your responses. Your name will not appear in any thesis or report resulting from this study; however, anonymous quotations may be used. Data will be deleted and destroyed after 10 years.

VOLUNTARY PARTICIPATION

Participation in this study is strictly voluntary, and the choice of whether to participate or not is up to you. You have the right to forfeit answering any question(s) you choose while still remaining in the study, as well as the right to withdraw from the study at any time, or in any round without penalty which can be done by emailing the researcher at crampj@yorku.ca and stating that you wish to withdraw from the study, or by not completing the survey(s). Your decision to stop participating, or to refuse to answer

particular questions will not affect your relationship with the researchers, York University, or any other group associated with this project. In the event that you withdraw from the study, all associated data collected will be immediately destroyed wherever possible.

ACCESSING FINDINGS OF THIS STUDY/ PUBLICATION OF RESULTS

Results of this study may be published in professional journals and presented at conferences. You will also have the option to receive a summary of results, as per your request.

Appendix K: ***Participant Demographic Questionnaire (Study two)***

Demographic Survey Questionnaire- Round 1 (Men with Spinal Cord Injury)

1. What is your age?
_____

2. What was your age at the time of your injury?
_____

3. How long have you been living with spinal cord injury?
_____

4. What is the level/ classification of your injury?
_____

5. What ethnic background do you most identify with?
_____

5. Were you born in Canada?
_____

6. What is your sexual orientation?
_____

7. Did you participate in sexual activities prior to your injury? (any intimate act or expression of sexuality, not limited specifically intercourse)

Yes
No

8. Did you have sexual intercourse prior to your SCI?

Yes
No

9. Have you participated in sexual activities since your SCI? (any intimate act or expression of sexuality, not limited specifically intercourse)

Yes
No
10. Have you had sexual intercourse since your SCI?

Yes
No

11. What is your current relationship status?

a. Married (not separated)

b. Common-law
c. In a relationship (not living together)
d. Separated
e. Divorced
f. Widowed
g. Single (never legally married)

12. What was your relationship status at the time of your injury?

a. Married (not separated)
b. Common-law
c. In a relationship (not living together)
d. Separated
e. Divorced
f. Widowed
g. Single (never legally married)

13. Do you have any children? How many?

a. No

b. Yes

Number of children before spinal cord injury? _____

Number of children after spinal cord injury? _____

14. What is your highest level of education?

a. Elementary school or less
b. Some high school
c. Completed high school
d. Some college or technical school
e. Completed college or technical school
f. Some university
g. Completed Bachelor's degree
h. Graduate Degree

15. What is your current employment status?

a. Employed full time
b. Employed part time
c. Retired
d. Student
Please specify job title/ degree: _____
e. On Disability
f. Unemployed

16. What was your employment status at the time of your injury?

a. Employed full time
b. Employed part time
c. Retired
d. Student
Please specify job title/ degree: _____
e. Unemployed

17. What is your best estimate of your total household income before taxes?

a. Under $9,999
b. $10,000 - $19,999
c. $20,000 - $29,999
d. $30,000 - $39,999
e. $40,000 - $49,999
f. $50,000 - $59,999
g. $60,000 - $69,999
h. $70,000 - $79,999
i. $80,000 - $89,999
j. $90,000 - $99,999
k. $100,000 - $124,999
l. $125,000 - 149,999
j. $150,000 - $174,999
k. $175,000 - $199,999
l. over $200,000

18. Please rate your overall health within the past 4 months:

a. Excellent
b. Good
c. Fair
d. Poor

19. Overall, how sexually satisfied have you felt over the past 4 months?

a. Very satisfied
b. Satisfied
c. Neither satisfied or dissatisfied
d. Dissatisfied
e. Very dissatisfied

Appendix L: ***Consent Form and Delphi Survey (Study two)***

CONSENT FORM

I agree to participate in the study described above and I have made this decision voluntarily based on the information provided in the Information-Consent Letter. The study has been explained to me, and any questions I had have all been answered to my contentment. I understand that I may ask additional questions in the future, and that I maintain the right to withdraw this consent at any time.

Yes •
No •

Online Survey Introduction
Men with Spinal Cord Injury

Hello,

Thank you for agreeing to participate in a three-round Delphi exercise for this research project. You are one of 20 panelists, and each of you has been selected on the basis of your experience and expertise with regards to the research topic.

Please complete the participant information form at the beginning of the survey. Your participation will be confidential, and the identity of all panelists will remain confidential at all times. No one else will be able to see your responses, and your details will not be referred to in any presentations of the results. Direct quotations from free text answers may be used, but they will be anonymous and will not traceable back to you.

Using the Delphi method, this study aims to identify the most important psychological and emotional concerns regarding sexuality among men with spinal cord injury. When the term *sexuality* is used, it is referring to the way you express yourself sexually and could be anything from the emotional intimacy experienced with a partner to the act of sexual intercourse, and everything in between unless specified otherwise. When the term *sex* is used, it is referring to physical sexual activities. The Delphi process involves questioning the panel on three separate occasions to reach a level of agreement and group consensus on this topic based on the opinions of experts.

Round 1 (included here) is designed to identify and confirm key issues, as well as to obtain your personal opinion relating to these topics.

For each question, we would like you to choose a response that best represents your opinion. There are no right or wrong answers. It is your judgement as an expert panelist that we are interested in. You may also write a few words about your answer in the text boxes provided. You may choose not to answer any questions that make you uncomfortable. Please complete and submit your survey online within seven days of receiving it.

Please begin the survey when you are ready.

Delphi Survey- Round 1 (Men with Spinal Cord Injury)

Section 1: Emergence of a new meaning of sexuality and masculinity

Strongly Agree/ Agree/ Slightly Agree/ Neither Agree or Disagree/ Slightly Disagree/ Disagree/ Strongly Disagree

a. I believe that sex is both a physical and a psychological/ emotional experience
b. I believe that sexuality is about more than just sex
c. I think that sex involves more than just penetration
d. Sex has less to do with penetration since my SCI
e. Emotional closeness with my partner during sex has become more important since my SCI
f. Physical closeness (touching, cuddling, laying together) to my sexual partner has become more important than the act of penetration since my SCI
g. I think the sexual experience is more enjoyable when there is an emotional/ psychological connection with my partner rather than just a physical connection
h. If I put more focus on the emotional/ psychological connection with my partner, the sexual experience can be more satisfying than it was prior to my SCI
i. Finding new ways to experience sexual satisfaction has become more important since my SCI
j. Open and honest communication with my partner about sex has become more important since my SCI
k. I focus more on my partner's sexual satisfaction since my SCI
l. I get sexual satisfaction through my partner's sexual satisfaction
m. I think that men with SCI are viewed as less masculine than men who are able-bodied
n. The way I view my own masculinity has changed since my SCI

Additional Comments (optional): _____

Section 2: Fears: psychological/ physical

Strongly Agree/ Agree/ Slightly Agree/ Neither Agree or Disagree/ Slightly Disagree/ Disagree/ Strongly Disagree

a. People only see my SCI when they first look at me
b. I avoid approaching new potential partners because I am afraid of being rejected
c. I have questioned my ability to attract a partner
d. Because of my SCI, I am concerned for my physical safety when meeting new people
e. Dating is not worth the effort because I spend a lot of time explaining my injury and then the person is not interested anyway
f. I am afraid that I will have to settle in terms of the partner I end up with
g. People may not want to date me because they don't want to end up being my caregiver
h. I am afraid of letting my partner down sexually
i. I have a fear of failure when in a sexual situation
j. Changes in my body functions since my SCI have negatively affected my sexual life
k. Changes in my sexual function since my SCI have added stress to my relationships
l. Changes in my sexual function since my SCI have caused relationships to end
m. Changes to my level of independence after SCI have negatively affected my self-esteem
n. Changes to my level of confidence after SCI have negatively affected my sexuality
o. Changes in the way my body looks after SCI have had a negative effect on my sexuality

p. Body image issues that I have been concerned about include: (check all that apply)

- Loss of muscle tone
- Atrophied (smaller) legs
- Not being able to wear certain clothes
- Larger stomach
- Scars from injury/surgery
- Always being in a seated position
- Pressure sores
- Flaccid penis during sexual activities
- Other (specify)_____

q. Since my SCI, cleanliness of my body has been a concern during sexual activities

r. A fear of the following issues has prevented me from participating in sexual activities: (check all that apply)

- Bladder incontinence
- Bowel incontinence
- Autonomic dysreflexia (high blood pressure)
- Spasticity
- Pain
- Getting hurt
- Other (spcify)_____

s. My partner is afraid of hurting me during sex

t. I am anxious of the side effects of medications that would help me have an erection (eg Viagra, Cialis etc)

u. Having to monitor my body during sexual activities takes away from the sexual experience

v. Increased planning in my daily life due to SCI has had a negative effect on my sexual life

w. Decreased spontaneity in my sexual life due to SCI has had a negative effect on my sexual life

Additional Comments (optional): _____

<u>Section 3:</u> Impact of injury

a. I have experienced the following emotions since SCI that affect my sexuality: (check all that apply)

- Loneliness
- Anxiety
- Exhaustion/fatigue
- Frustration
- Anger
- Depression
- Mourning (sadness)
- Shame
- Embarrassment
- Amazement
- Pride
- Other (specify)_____

Strongly Agree/ Agree/ Slightly Agree/ Neither Agree or Disagree/ Slightly Disagree/ Disagree/ Strongly Disagree

b I try not to think about sexuality by refocusing my attention on other things

c. Negative sexual experiences after SCI:_____ (check all that apply)

- Decrease my confidence
- Have a negative effect on my overall quality of life
- Lead to avoidance (decreased participation) in sexual activities

d. Positive sexual experiences after SCI:_____ (check all that apply)

- Increase my confidence
- Give me hope for the future
- Help me accept my injury
- Have a positive effect on my overall quality of life
- Lead to increased participation in sexual activities

e. I feel like something is missing from my life when I think about my sexual experiences now compared to before my SCI

f. Positively adjusting to sexuality after SCI contributes to my personal growth

g. The longer I live with SCI, the more accepting I am of my injury

Additional Comments (optional): _____

Section 4: Education

Strongly Agree/ Agree/ Slightly Agree/ Neither Agree or Disagree/ Slightly Disagree/ Disagree/ Strongly

Disagree

a. I wanted to receive education about sex after SCI
b. I think it is important to receive education about sex after SCI
c. I am satisfied with the amount of information I received regarding sexuality after SCI
d. My health care providers are knowledgeable about sex after SCI
e. My health care providers are comfortable discussing sex after SCI with me
f. Most of my knowledge about sex after SCI came from my health care providers
g. Most of my knowledge about sex after SCI came from my own research
h. Sexual education was not a priority of my health care providers when I was in rehabilitation
i. I believe the information provided by health care professionals regarding sex after SCI is too clinical
j. I think the information provided by health care professionals regarding sex after SCI is missing the personal experience that comes with actually living with a SCI
k. I am satisfied with the resources that are available regarding sex after SCI
l. Increased sexual education after SCI could lead to increased sexual satisfaction
m. I am knowledgeable about alternate ways to achieve sexual satisfaction after SCI
n. I would find it helpful to receive information about the physical aspects of sexuality after SCI
o. I would find it helpful to receive information/ counselling about the psychological/emotional aspects of sexuality after SCI
p. I spend a lot of time educating my new potential partners about sex after SCI
q. It is difficult to have a conversation about how sex works after SCI with a new potential partner
r. There are adequate resources available for my partner to access to learn about sex after SCI
s. I am affected by the misconceptions that society has about men who live with a SCI
t. I had my own misconceptions about living with a SCI that I had to overcome after my injury
u. Educating society about what it actually means to live with SCI could improve the dating experience
v. The best time to receive information about sex after SCI is:_____ (check all that apply)

- Immediately after injury
- While in rehabilitation
- 0-6 months after injury
- 6-12 months after injury
- 1-2 years after injury
- More than 2 years after injury
- Immediately after injury and again once you are back in the community
- Ongoing
- I do not want to receive information about sex
- Other _____

w. I want to receive information about sex after SCI from:_____ (check all that apply)

- Doctor
- Nurse
- Physiotherapist
- Occupational therapist
- Psychologist
- Relationship counsellor
- Another man with SCI
- I do not want to receive information about sex
- Other _____

x. I would like to receive information about sex after SCI in the following way(s):_____ (check all that apply)

- Pamphlet
- Book
- Conversation with health care provider
- Video
- Group discussion
- Conversation with another man with SCI
- Internet
- I do not want to receive information about sex
- Other _____

Additional Comments (optional): _____

Appendix M: ***Recruitment Poster- Healthcare Providers (Study three)***

SEXUALITY AMONG MEN WITH SPINAL CORD INJURY:

HEALTH CARE PROVIDER PERSPECTIVE

Participants needed!

Receive a $10 gift card!

We are looking for **Health Care Providers (PT, OT, MD, nurse, psychologist, clinician, etc.) in Canada** who work with men who have a spinal cord injury to participate in a series of three confidential, **15-20 minute** online surveys focusing on the psychological concerns of sexuality for men after spinal cord injury.

If you are interested in participating, please contact Jackie Kathnelson, PhD Candidate, School of Kinesiology and Health Science, York University at crampj@yorku.ca

YORK UNIVERSITÉ UNIVERSITY

This file has been reviewed and received ethics clearance from the York University Research Ethics Board (2019-004) 416-736-5914; ore@yorku.ca and the Brock University Research Ethics Board (18-235) 905-688-5550 Ext. 3035; reb@brocku.ca

SCI study crampj@yorku.ca

Appendix N: ***Participant Information Letter (Study three)***

Letter of Invitation and Consent Form

Using the Delphi Method to Identify Top Psychological and Emotional Concerns of Sexuality Among Men After Spinal Cord Injury:
A Health Care Provider Perspective

Please consider this an invitation to voluntarily participate in a research investigation examining the top psychological and emotional concerns of sexuality among men with spinal cord injury. This study will be directed by Dr. William Gage in the School of Kinesiology and Health Science at York University. In this letter, you will find a detailed description of the study that will assist you in your decision to either participate, or not participate in this study. Please take a minute to carefully read through this letter. Do not hesitate to ask for clarification, or to ask any questions you may have regarding either this letter or the study. Should you require further information, please contact the principle student investigator or the faculty supervisor using the contact information provided below.

Principle Student Investigator: Jackie Kathnelson, PhD Candidate
School of Kinesiology and Health Science, York University; crampj@yorku.ca
Faculty Supervisor: Dr. William Gage, Professor
School of Kinesiology and Health Science, York University; whgage@yorku.ca

This study has received clearance from the York University Research Ethics Board (File number 2019-004) and the Brock University Research Ethics Board (File number 18-235) and conforms to research ethics protocols by the Human Participants Review Subcommittee (HPRC) of York University and TCPS2. Should you require further information regarding the ethical approval of this study, or about your rights as a participant in this study, please contact the Sr. Manager & Policy Advisor for the Office of Research Ethics, 5th Floor, Kaneff Tower, York University (telephone 416-736-5914 or e-mail ore@yorku.ca) or Manager, Office of Research Ethics, York University, 309 York Lanes, phone 416-736-5914. You may also contact the Research Ethics Officer at Brock University (telephone 905-688-5550 ext. 3035 or e-mail reb@brocku.ca).

PURPOSE OF THE STUDY

The purpose of this study is to determine whether the most important psychological and emotional concerns regarding sexuality among men with spinal cord injury (SCI) as they are perceived by health

care providers who work with men who have SCI are the same as the most important concerns reported by men living with SCI. Using the Delphi Method, our aim is to generate a level of agreement regarding the importance of these issues based on the opinions of our expert panelists. Once we have determined if the concerns ranked highest in priority by health care providers match the top ranked concerns reported by men with SCI, we can direct future research towards to improving sexual education and sexual adjustment for men after SCI.

WHY HAVE YOU BEEN CHOSEN?

You have been chosen to participate in this study as an expert panelist because you have been identified as having an important perspective and relevant expertise in this topic. Your opinion is valuable to the research investigation.

STUDY PROCEDURES

Should you choose to participate in this study, you will be asked to complete a Delphi exercise involving a 15-20 minute online survey on three separate occasions. You will be asked to complete and submit each survey within one week. In round one, you will be asked to provide responses and ratings to a series of questions. Once we receive all responses from all expert panelists, we will collate and summarize the findings, and based on the comments provided and answers given, we will formulate the round two survey. In round two, you will again be asked to rate a series of questions. In round three, you will receive information about the average responses of other panelists, and with that information, you will be given the opportunity to revise your answers. It is important that you complete all three rounds. The aim is for the Delphi exercise to build understanding and consensus around the top priorities.

POTENTIAL RISKS

Participation in this study is not associated with any potential risks. Please keep in mind that you can choose not to answer any question(s) that make you feel uncomfortable.

POTENTIAL BENEFITS

Potential benefits of participating in this study include the opportunity to reflect on your own feelings regarding this very important topic and having the opportunity to consider your opinion of the top psychological and emotional concerns regarding sexuality among men with SCI in relation to the opinions of other health care providers. The information collected during this investigation may have the ability to guide future research and/or best-practice guidelines to ensure the areas being targeted by researchers and health care providers represent the main concerns of the men they aim to help.

COMPENSATION

There will be no financial compensation for participation in this study.

CONFIDENTIALITY

The information you provide and your individual responses will be kept confidential. All data will be stored securely and will be accessible only by the Principal Student Investigator. Other panelists will not be able to see your responses. Your name will not appear in any thesis or report resulting from this study; however, anonymous quotations may be used. Data will be deleted and destroyed after 10 years.

VOLUNTARY PARTICIPATION

Participation in this study is strictly voluntary, and the choice of whether to participate or not is up to you. You have the right to forfeit answering any question(s) you choose while still remaining in the study, as well as the right to withdraw from the study at any time, or in any round without penalty which can be done by emailing the researcher at crampj@yorku.ca and stating that you wish to withdraw from the study, or by not completing the survey(s). Your decision to stop participating, or to refuse to answer particular questions will not affect your relationship with the researchers, York University, or any other group associated with this project. In the event that you withdraw from the study, all associated data collected will be immediately destroyed wherever possible.

ACCESSING FINDINGS OF THIS STUDY/ PUBLICATION OF RESULTS

Results of this study may be published in professional journals and presented at conferences. You will also have the option to receive a summary of results, as per your request.

Appendix O: ***Participant Demographic Questionnaire (Study three)***

Demographic Survey Questionnaire- Round 1 (Health care providers)

1. What is your age?

    a. 20 years or younger
    b. 21 - 30
    c. 31 - 40
    d. 41 - 50
    e. 51 - 60
    f. 61 years or older

2. What is your highest level of education?

    a. Elementary school or less
    b. Some high school
    c. Completed high school
    d. Some college or technical school
    e. Completed college or technical school
    f. Some university
    g. Completed Bachelor's degree
    h. Graduate Degree

3. What is your occupation?
_____

4. How long have you been working in this occupation?

    a. Less than a year
    b. 1 - 5 years
    c. 6 - 10 years
    d. 11 - 15 years
    e. 16 - 20 years
    f. 21 - 25 years
    g. 26 years or more

5. What ethnic background do you most identify with?
_____

6. Were you born in Canada?

    a. Yes
    b. No

7. What is your gender?
_____

8. What is your sexual orientation?
_____

9. What is your current relationship status?

a. Married (not separated)
b. Common-law
c. In a relationship (not living together)
d. Separated
e. Divorced
f. Widowed
g. Single (never legally married)

Appendix P: ***Consent Form and Delphi Survey (Study three)***

CONSENT FORM

I agree to participate in the study described above and I have made this decision voluntarily based on the information provided in the Information-Consent Letter. The study has been explained to me, and any questions I had have all been answered to my contentment. I understand that I may ask additional questions in the future, and that I maintain the right to withdraw this consent at any time.

Yes •
No •

Online Survey Introduction
Health Care Providers

Hello,

Thank you for agreeing to participate in a three-round Delphi exercise for this research project. You are one of 10 panelists, and each of you has been selected on the basis of your experience and expertise with regards to the research topic.

Please complete the participant information form at the beginning of the survey. Your participation will be confidential, and the identity of all panelists will remain confidential at all times. No one else will be able to see your responses, and your details will not be referred to in any presentations of the results. Direct quotations from free text answers may be used, but they will be anonymous and will not traceable back to you.

Using the Delphi method, this study aims to identify the most important psychological and emotional concerns regarding sexuality among men with spinal cord injury. When the term *sexuality* is used, it is referring to the way one expresses themself sexually and could be anything from the emotional intimacy experienced with a partner to the act of sexual intercourse, and everything in between unless specified otherwise. When the term *sex* is used, it is referring to physical sexual activities. The Delphi process involves questioning the panel on three separate occasions to reach a level of agreement and group consensus on this topic based on the opinions of experts.

Round 1 (included here) is designed to identify and confirm key issues, as well as to obtain your personal opinion relating to these topics.

For each question, we would like you to choose a response that best represents your opinion. There are no right or wrong answers. It is your judgement as an expert panelist that we are interested in. You may also write a few words about your answer in the text boxes provided. You may choose not to answer any questions that make you uncomfortable. Please complete and submit your survey online within seven days of receiving it.

Please begin the survey when you are ready.

Delphi Survey- Round 1 (Health Care Providers)

Section 1: Emergence of a new meaning of sexuality and masculinity

Strongly Agree/ Agree/ Slightly Agree/ Neither Agree or Disagree/ Slightly Disagree/ Disagree/ Strongly Disagree

a. Men with SCI believe that sex is both a physical and psychological/ emotional experience
b. Men with SCI believe that sexuality is about more than just sex
c. Men with SCI believe that sex involves more than just penetration
d. Men with SCI think that sex has less to do with penetration than it did before injury
e. Men with SCI think that emotional closeness with a partner during sex is more important after their injury
f. Men with SCI think that physical closeness (touching, cuddling, laying together) with a sexual partner is more important than the act of penetration after their injury
g. Men with SCI think the sexual experience is more enjoyable when there is an emotional/ psychological connection with a partner rather than just a physical connection
h. Men with SCI think that by putting more focus on the emotional/ psychological connection with a partner, the sexual experience can be more satisfying than it was prior to their injury
i. Men with SCI believe that finding new ways to experience sexual satisfaction is more important after injury
j. Men with SCI believe that open and honest communication with a partner about sex is more important after their injury
k. Men with SCI say they focus more on their partner's sexual satisfaction after their injury
l. Men with SCI say they get sexual satisfaction through their partner's sexual satisfaction
m. Men with SCI think that they are viewed as less masculine than men who are able-bodied
n. Men with SCI say the way they view their own masculinity has changed since their injury

Additional Comments (optional): _____

Section 2: Fears: psychological/ physical

Strongly Agree/ Agree/ Slightly Agree/ Neither Agree or Disagree/ Slightly Disagree/ Disagree/ Strongly Disagree

a. Men with SCI think that people only see their SCI when they first look at them
b. Men with SCI say they avoid approaching new potential partners because they are afraid of being rejected
c. Men with SCI report that they have questioned their ability to attract a partner
d. Men with SCI say that because of their injury, they are concerned for their physical safety when meeting new people
e. Men with SCI think that dating is not worth the effort because they spend a lot of time explaining their injury and then the person is not interested anyway
f. Men with SCI report that they are afraid they will have to settle in terms of the partner they end up with
g. Men with SCI feel that people may not want to date them because they don't want to end up being their caregiver
h. Men with SCI say they are afraid of letting their partner down sexually

i. Men with SCI report having a fear of failure when in a sexual situation
j. Men with SCI feel that changes in their body functions since injury have negatively affected their sexual life
k. Men with SCI feel that changes in their sexual function since injury have added stress to their relationships
l. Men with SCI feel that changes in their sexual function since injury have caused relationships to end
m. Men with SCI feel that changes to their level of independence after SCI have negatively affected their self-esteem
n. Men with SCI feel that changes to their level of confidence after SCI have negatively affected their sexuality
o. Men with SCI feel that changes in the way their body looks after SCI have had a negative effect on their sexuality
p. Men with SCI report body image issues that they have been concerned about including: (check all that apply)

- Loss of muscle tone
- Atrophied (smaller) legs
- Not being able to wear certain clothes
- Larger stomach
- Scars from injury/surgery
- Always being in a seated position
- Pressure sores
- Flaccid penis during sexual activities
- Other (specify)_____

q. Men with SCI feel that cleanliness of their body has been a concern during sexual activities since injury
r. Men with SCI report a fear of the following issues has prevented them from participating in sexual activities: (check all that apply)

- Bladder incontinence
- Bowel incontinence
- Autonomic dysreflexia (high blood pressure)
- Spasticity
- Pain
- Getting hurt
- Other (specify)_____

s. Men with SCI think that their partner is afraid of hurting them during sex
t. Men with SCI feel anxious about the side effects of medications that would help them have an erection (eg Viagra, Cialis etc)
u. Men with SCI feel that having to monitor their body during sexual activities takes away from the sexual experience
v. Men with SCI think that increased planning in their daily life due to injury has had a negative effect on their sexual life
w. Men with SCI think that decreased spontaneity in their sexual life due to injury has had a negative effect on their sexual life

Additional Comments (optional): _____

<u>Section 3:</u> Impact of injury

a. Men with SCI report experiencing the following emotions since injury that affect their sexuality: (check all that apply)

- Loneliness
- Anxiety
- Exhaustion/fatigue
- Frustration
- Anger
- Depression
- Mourning (sadness)
- Shame
- Embarrassment
- Amazement
- Pride
- Other (specify)_____

Strongly Agree/ Agree/ Slightly Agree/ Neither Agree or Disagree/ Slightly Disagree/ Disagree/ Strongly Disagree
b. Men with SCI say they try not to think about sexuality by refocusing their attention on other things

c. Men with SCI report that negative sexual experiences after injury:_____
(check all that apply)
- Decrease their confidence
- Have a negative effect on their overall quality of life
- Lead to avoidance (decreased participation) in sexual activities

d. Men with SCI report that positive sexual experiences after injury:_____
(check all that apply)
- Increase their confidence
- Give them hope for the future
- Help them accept their injury
- Have a positive effect on their overall quality of life
- Lead to increased participation in sexual activities

e. Men with SCI feel like something is missing from their life when they think about their sexual experiences now compared to before injury
f. Men with SCI believe that positively adjusting to sexuality after injury contributes to their personal growth
g. Men with SCI feel that the longer they live with their injury, the more accepting they are of it

Additional Comments (optional): _____

Section 4: Education

Strongly Agree/ Agree/ Slightly Agree/ Neither Agree or Disagree/ Slightly Disagree/ Disagree/ Strongly Disagree

a. Men with SCI say they want to receive education about sex after injury
b. Men with SCI think it is important to receive education about sex after injury
c. Men with SCI feel satisfied with the amount of information they received regarding sexuality after injury
d. Men with SCI feel that their health care providers are knowledgeable about sex after injury
e. Men with SCI feel that their health care providers are comfortable discussing sex after injury with them
f. Men with SCI report that most of their knowledge about sex after injury came from their health care providers
g. Men with SCI report that most of their knowledge about sex after injury came from their own research
h. Men with SCI feel that sexual education was not a priority of their health care providers when they were in rehabilitation
i. Men with SCI believe the information provided by health care professionals regarding sex after injury is too clinical
j. Men with SCI think the information provided by health care professionals regarding sex after injury is missing the personal experience that comes with actually living with a SCI
k. Men with SCI report being satisfied with the resources that are available regarding sex after injury
l. Men with SCI think that increased sexual education after injury could lead to increased sexual satisfaction
m. Men with SCI feel that they are knowledgeable about alternate ways to achieve sexual satisfaction after injury
n. Men with SCI think that it would be helpful to receive information about the physical aspects of sexuality after injury
o. Men with SCI think it would be helpful to receive information/ counselling about the psychological/ emotional aspects of sexuality after injury
p. Men with SCI report spending a lot of time educating new potential partners about sex after injury

q. Men with SCI feel that it is difficult to have a conversation about how sex works after injury with a new potential partner
r. Men with SCI think that there are adequate resources available for their partner to access to learn about sex after injury
s. Men with SCI report being affected by the misconceptions that society has about men who live with a SCI
t. Men with SCI report having their own misconceptions about living with a SCI that they have to overcome after their injury
u. Men with SCI believe that educating society about what it actually means to live with this injury could improve their dating experience
v. Men with SCI report that the best time to receive information about sex after injury is:_____ (check all that apply)

- Immediately after injury
- While in rehabilitation
- 0-6 months after injury
- 6-12 months after injury
- 1-2 years after injury
- More than 2 years after injury
- Immediately after injury and again once they are back in the community
- Ongoing
- Men with SCI do not wish to receive information about sex
- Other _____

w. Men with SCI report that they would want to receive information about sex after injury from:_____ (check all that apply)

- Doctor
- Nurse
- Physiotherapist
- Occupational therapist
- Psychologist
- Relationship counsellor
- Another man with SCI
- Men with SCI do not wish to receive information about sex
- Other _____

x. Men with SCI report that they would like to receive information about sex after injury in the following way(s):_____ (check all that apply)

- Pamphlet
- Book
- Conversation with health care provider
- Video
- Group discussion
- Conversation with another man with SCI
- Internet
- Men with SCI do not wish to receive information about sex
- Other _____

Additional Comments (optional): _____

Appendix Q: ***Men versus Healthcare Provider Delphi Results***

***Minimum of 70% in either end of a 7-point Likert (strongly agree/agree/somewhat agree OR strongly disagree/disagree/somewhat disagree) to achieve consensus; defined a priori**
****Minimum of 70% in either end of a 7-point Likert (agree/strongly agree OR disagree/strongly disagree) to achieve high positive or high negative consensus; defined a priori**

Question	**Men:** ***Level of Agreement***	**Men:** ***Percent Agreement***	**Question**	**Healthcare Provider:** ***Level of Agreement***	**Healthcare Provider:** ***Percent Agreement***
I believe that sex is both a physical and a psychological/ emotional experience	Strong agreement	95% high positive 100% positive end	Men with SCI believe that sex is both a physical and psychological/ emotional experience	Strong agreement	84.6% high positive 100% positive end
I believe that sexuality is about more than just sex	Strong agreement	95% high positive 95% positive end	Men with SCI believe that sexuality is about more than just sex	Strong agreement	92.3% high positive 100% positive end
I think that sex involves more than just penetration	Strong agreement	95% high positive 100% positive end	Men with SCI believe that sex involves more than just penetration	Moderate agreement	38.5% high positive 92.3% positive end
Sex has less to do with penetration since my SCI	Moderate agreement	43% high positive 79% positive end	In general, men with SCI think that sex has less to do with penetration than it did before injury	Moderate agreement	55% high positive 91% positive end
Emotional closeness with my partner during sex has become more important since my SCI	Moderate agreement	45% high positive 70% positive end	Men with SCI think that emotional closeness with a partner during sex is more	Moderate agreement	53.84% high positive 92.3% positive end

			important after their injury		
Physical closeness (touching, cuddling, laying together) to my sexual partner has become more important than the act of penetration since my SCI	Moderate agreement	50% high positive 71% positive end	In general, men with SCI think that physical closeness (touching, cuddling, laying together) with a sexual partner is more important than the act of penetration after their injury	Moderate agreement	22.2% high positive 77.8% positive end
I think the sexual experience is more enjoyable when there is an emotional/ psychological connection with my partner rather than just a physical connection	Strong agreement	95% high positive	Men with SCI think the sexual experience is more enjoyable when there is an emotional/ psychological connection with a partner rather than just a physical connection	Strong agreement	70% high positive 100% positive end
If I put more focus on the emotional/ psychological connection with my partner, the sexual experience can be more satisfying than it was prior to my SCI	None	57% positive end	In general, men with SCI think that by putting more focus on the emotional/ psychological connection with a partner, the sexual experience can be more satisfying than	Moderate agreement	33.3 high positive 88.9% positive end

			it was prior to their injury		
Finding new ways to experience sexual satisfaction has become more important since my SCI	Moderate agreement	80% positive end	Men with SCI believe that finding new ways to experience sexual satisfaction is more important after injury	Moderate agreement	61.5% high positive 100% positive end
Open and honest communication with my partner about sex has become more important since my SCI	Strong agreement	70% high positive 80% positive end	Men with SCI believe that open and honest communicatio n with a partner about sex is more important after their injury	Moderate agreement	61.5% high positive 76.9% positive end
I focus more on my partner's sexual satisfaction since my SCI	Strong agreement	70% high positive 75% positive end	In general, men with SCI say they focus more on their partner's sexual satisfaction after their injury	None	70% neither agree or disagree 30% positive end
I get sexual satisfaction through my partner's sexual satisfaction	Strong agreement	90% high positive	Men with SCI say they get sexual satisfaction through their partner's sexual satisfaction	Moderate agreement	23.1% high positive 70% positive end
I think that men with SCI are viewed as less masculine than men who are able-bodied	Moderate agreement	63% high positive 75% positive end	In general, men with SCI think that they are viewed as less masculine than men who	Moderate agreement	44.4 high positive 100% positive end

			are able-bodied		
The way I view my own masculinity has changed since my SCI	Moderate agreement	75% positive end	Men with SCI say the way they view their own masculinity has changed since their injury	Moderate agreement	61.5% high positive 92.3% positive end
People only see my SCI when they first look at me	Moderate agreement	75% positive end	Men with SCI think that people only see their SCI when they first look at them	Strong agreement	70% high positive 100% positive end
I avoid approaching new potential partners because I am afraid of being rejected	Moderate agreement	50% high positive 70% positive end	Men with SCI say they avoid approaching new potential partners because they are afraid of being rejected	Moderate agreement	53.8% high positive 84.6% positive end
I have questioned my ability to attract a partner	Moderate agreement	58% high positive 75% positive end	Men with SCI report that they have questioned their ability to attract a partner	Moderate agreement	53.6% high positive 92.3% positive end
I am afraid that I will have to settle in terms of the partner I end up with	None	50% negative end	Men with SCI report that they are afraid they will have to settle in terms of the partner they end up with	Moderate agreement	46.1% high positive 84.6% positive end
Because of my SCI, I am concerned for my physical safety when meeting new people	Strong dis-agreement	80% high negative 85% negative end	In general, men with SCI say that because of their injury, they are concerned for	Moderate dis-agreement	50% high negative 70% negative end

			their physical safety when meeting new people		
Dating is not worth the effort because I spend a lot of time explaining my injury and then the person is not interested anyway	Moderate agreement	62% high positive 70% positive end	Men with SCI think that dating is not worth the effort because they spend a lot of time explaining their injury and then the person is not interested anyway	Moderate dis-agreement	38.5% high negative 76.9% negative end
People may not want to date me because they don't want to end up being my caregiver	Moderate agreement	25% high positive 70% positive end	At some point since their injury, men with SCI feel that people may not want to date them because they don't want to end up being their caregiver	Moderate agreement	12.5% high positive 87.5% positive end
I am afraid of letting my partner down sexually	Moderate agreement	50% high positive 81% positive end	Men with SCI say they are afraid of letting their partner down sexually	Moderate agreement	38.5% high positive 70% positive end
I have a fear of failure when in a sexual situation	None	47% positive end	Men with SCI report having a fear of failure when in a sexual situation	Moderate agreement	30.8% high positive 76.9% positive end
Changes in my body functions since my SCI have negatively affected my sexual life	Strong agreement	75% high positive 85% positive end	Men with SCI feel that changes in their body functions since injury have	Moderate agreement	53.9% high positive 76.9% positive end

			negatively affected their sexual life		
Changes in my sexual function since my SCI have added stress to my relationships	Moderate agreement	70% positive end	Men with SCI feel that changes in their sexual function since injury have added stress to their relationships	Moderate agreement	53.9% high positive 100% positive end
Changes in my sexual function since my SCI have caused relationships to end	None	46% negative end	At some point since their injury, men with SCI feel that changes in their sexual function since injury have caused relationships to end	Moderate agreement	37.5% high positive 87.5% positive end
Changes to my level of independence after SCI have negatively affected my self-esteem	Moderate agreement	60% high positive 73% positive end	Men with SCI feel that changes to their level of independence after SCI have negatively affected their self-esteem	Moderate agreement	46.2% high positive 84.6% positive end
Changes to my level of confidence after SCI have negatively affected my sexuality	Moderate agreement	47% high positive 75% positive end	Men with SCI feel that changes to their level of confidence after SCI have negatively affected their sexuality	Moderate agreement	38.5% high positive 84.6% positive end
Changes in the way my body looks after SCI have had a	Moderate agreement	44% high positive 75% positive end	At some point since their injury, men with SCI feel that changes in	Moderate agreement	64% high positive 91% positive end

negative effect on my sexuality			the way their body looks after SCI have had a negative effect on their sexuality		
Since my SCI, cleanliness of my body has been a concern during sexual activities	None	60% negative end	At some point since their injury, men with SCI feel that cleanliness of their body has been a concern during sexual activities since injury	Strong agreement	73% high positive 82% positive end
My partner is afraid of hurting me during sex	Moderate dis-agreement	70% negative end	At some point since their injury, men with SCI think that their partner is afraid of hurting them during sex	Moderate agreement	55% high positive 91% positive end
I am anxious of the side effects of medications that would help me have an erection (eg Viagra, Cialis etc)	None	47% positive end	In general, men with SCI feel anxious about the side effects of medications that would help them have an erection (eg Viagra, Cialis etc)	None	45% positive end
Having to monitor my body during sexual activities takes away from the sexual experience	Moderate agreement	33% high positive 73% positive end	Men with SCI feel that having to monitor their body during sexual activities takes away from the	Moderate agreement	30.8% high positive 76.9% positive end

			sexual experience		
Increased planning in my daily life due to SCI has had a negative effect on my sexual life	None	67% positive end	Men with SCI think that increased planning in their daily life due to injury has had a negative effect on their sexual life	Moderate agreement	23.1% high positive 70% positive end
Decreased spontaneity in my sexual life due to SCI has had a negative effect on my sexual life	Moderate agreement	85% positive end	Men with SCI think that decreased spontaneity in their sexual life due to injury has had a negative effect on their sexual life	Moderate agreement	38.5% high positive 84.6% positive end
I try not to think about sexuality by refocusing my attention on other things	Moderate dis-agreement	53% high negative 73% negative end	In general, men with SCI say they try not to think about sexuality by refocusing their attention on other things	None	45% positive end
I feel like something is missing from my life when I think about my sexual experiences now compared to before my SCI	Strong agreement	80% high positive 93% positive end	Men with SCI feel like something is missing from their life when they think about their sexual experiences now compared to before injury	Moderate agreement	46.2% high positive 70% positive end
Positively adjusting to sexuality after SCI contributes	Moderate agreement	85% positive end	Men with SCI believe that positively adjusting to	Moderate agreement	50% high positive 91.7% positive end

to my personal growth			sexuality after injury contributes to their personal growth		
The longer I live with SCI, the more accepting I am of my injury	Moderate agreement	80% positive end	Men with SCI feel that the longer they live with their injury, the more accepting they are of it	Moderate agreement	53.8% high positive 84.6% positive end
I wanted to receive education about sex after SCI	Strong agreement	70% high positive 80% positive end	Men with SCI say they want to receive education about sex after injury	Strong agreement	75% high positive 91.7% positive end
I think it is important to receive education about sex after SCI	Strong agreement	80% high positive 90% positive end	Men with SCI think it is important to receive education about sex after injury	Strong agreement	90.9% high positive 100% positive end
I am satisfied with the amount of information I received regarding sexuality after SCI	None	53% negative end	Men with SCI feel satisfied with the amount of information they received regarding sexuality after injury	Moderate dis-agreement	33.3% high negative 75% negative end
I would find it helpful to receive information about the physical aspects of sexuality after SCI	Moderate agreement	75% positive end	Men with SCI think that it would be helpful to receive information about the physical aspects of sexuality after injury	Strong agreement	75% high positive 100% positive end

I would find it helpful to receive information/ counselling about the psychological/e motional aspects of sexuality after SCI	Moderate agreement	70% positive end	Men with SCI think it would be helpful to receive information/ counselling about the psychological/ emotional aspects of sexuality after injury	Strong agreement	75% high positive 100% positive end
My health care providers are knowledgeable about sex after SCI	Moderate dis-agreement	62% high negative 77% negative end	In general, men with SCI feel that their health care providers are knowledgeable about sex after injury	Moderate dis-agreement	37.5% high negative 87.5% negative end
My health care providers are comfortable discussing sex after SCI with me	None	50% negative end	In general, men with SCI feel that their health care providers are comfortable discussing sex after injury with them	Strong dis-agreement	73% high negative 91% negative end
Most of my knowledge about sex after SCI came from my health care providers	Strong dis-agreement	80% high negative 85% negative end	In general, men with SCI report that most of their knowledge about sex after injury came from their health care providers	Moderate dis-agreement	62.5% high negative 87.5% negative end
Most of my knowledge about sex after SCI came from my own research	Strong dis-agreement	75% high positive 85% positive end	Men with SCI report that most of their knowledge about sex after injury came	Strong agreement	75% high positive 91.7% positive end

			from their own research		
Sexual education was not a priority of my health care providers when I was in rehabilitation	Moderate agreement	63% high positive 88% positive end	Men with SCI feel that sexual education was not a priority of their health care providers when they were in rehabilitation	Moderate agreement	66.7% high positive 91.7% positive end
I believe the information provided by health care professionals regarding sex after SCI is too clinical	Moderate agreement	39% high positive 77% positive end	Men with SCI believe the information provided by health care professionals regarding sex after injury is too clinical	Moderate agreement	50% high positive 83.3% positive end
I think the information provided by health care professionals regarding sex after SCI is missing the personal experience that comes with actually living with a SCI	Moderate agreement	80% positive end	Men with SCI think the information provided by health care professionals regarding sex after injury is missing the personal experience that comes with actually living with a SCI	Moderate agreement	66.7% high positive 75% positive end
I am satisfied with the resources that are available regarding sex after SCI	None	60% negative end	In general, men with SCI report being satisfied with the resources that are available regarding sex after injury	Moderate dis-agreement	62.5% high negative 87.5% negative end
Increased sexual education after SCI could lead	Moderate agreement	75% positive end	Men with SCI think that increased	Moderate agreement	66.7% high positive

to increased sexual satisfaction			sexual education after injury could lead		100% positive end
I am knowledgeable about alternate ways to achieve sexual satisfaction after SCI	Moderate agreement	70% positive end	In general, men with SCI feel that they are knowledgeable about alternate ways to achieve sexual satisfaction after injury	Moderate dis-agreement	50% high negative 75% negative end
I spend a lot of time educating my new potential partners about sex after SCI	None	46% positive end	Men with SCI report spending a lot of time educating new potential partners about sex after injury	Moderate agreement	50% high positive 83.3% positive end
It is difficult to have a conversation about how sex works after SCI with a new potential partner	None	57% negative end	Men with SCI feel that it is difficult to have a conversation about how sex works after injury with a new potential partner	Moderate agreement	50% high positive 83.3% positive end
There are adequate resources available for my partner to access to learn about sex after SCI	None	64% negative end	In general, men with SCI think that there are adequate resources available for their partner to access to learn about sex after injury	Moderate dis-agreement	62.5% high negative 75% negative end
I am affected by the misconceptions that society has	Moderate agreement	75% positive end	Men with SCI report being affected by the misconception	Moderate agreement	58.3% high positive 100% positive end

about men who live with a SCI			s that society has about men who live with a SCI		
I had my own misconceptions about living with a SCI that I had to overcome after my injury	Moderate agreement	56% high positive 86% positive end	Men with SCI report having their own misconception s about living with a SCI that they have to overcome after their injury	Moderate agreement	58.3% high positive 100% positive end
Educating society about what it actually means to live with SCI could improve the dating experience	Moderate agreement	80% positive end	Men with SCI believe that educating society about what it actually means to live with this injury could improve their dating experience	Moderate agreement	66.7% high positive 91.7% positive end
At some point since my SCI, I have questioned what would make me attractive to a partner	Moderate agreement	59% high positive 88% positive end	At some point since their injury, men with SCI have questioned what would make them attractive to their partner/potenti al partner	Moderate agreement	44.4% high positive 88.9% positive end
I have a lower sexual drive now than I did prior to my injury	None	60% positive end	In general, men with SCI have a lower sexual drive than they did prior to their injury	None	55% neither agree or disagree 36% negative end
At some point since my injury I have compared my body to men	Moderate agreement	65% high positive 82% positive end	At some point since their injury, men with SCI have compared their	Strong agreement	88.9% high positive 100% positive end

who do not have a SCI			body to men who do not have a SCI		
At some point since my injury I have compared my sexual performance to men who do not have a SCI	None	60% positive end	At some point since their injury, men with SCI have compared their sexual performance to men who do not have a SCI	Strong agreement	88.9% high positive 100% positive end
Decreased self-esteem negatively affects my sexuality	Moderate agreement	24% high positive 76% positive end	In general, decreased self-esteem after SCI negatively affects sexuality for men with SCI	Moderate agreement	44.4% high positive 88.9% positive end
MEN:	Reached Consensus 50/65		Did Not Reach Consensus: 15/65		
Healthcare Providers:	Reached Consensus 61/65		Did Not Reach Consensus: 4/65		

* Strong agreement/disagreement - ≥70% of responses strongly (dis)agree or (dis)agree
* Moderate agreement/disagreement - ≥70% of responses strongly (dis)agree, (dis)agree or somewhat (dis)agree
***** High positive/negative - strongly (dis)agree or (dis)agree
* Positive/negative end - strongly (dis)agree, (dis)agree or somewhat (dis)agree

Appendix R: ***Body Issues and Sexual Experiences: Men versus Healthcare Provider Delphi Results***

	Percent Agreement	
	Men	**Healthcare Providers**
Body image issues that I have been concerned about include/ From the perspective of a healthcare provider who works with men who have a SCI, men with SCI would report that body image issues they have been concerned about include:		
Flaccid penis during sexual activities	80%	92%
Loss of muscle tone	65%	70%
Larger stomach	60%	77%
Always being in a seated position	50%	46%
Atrophied (smaller) legs	35%	54%
Pressure sores	30%	46%
Not being able to wear certain clothes	15%	31%
Scars from injury/ surgery	5%	23%
A fear of the following issues has prevented me from participating in sexual activities/ From the perspective of a healthcare provider who works with men who have a SCI, men with SCI would report a fear of the following issues has prevented them from participating in sexual activities:		
Bladder incontinence	50%	92%
Bowel incontinence	35%	92%
Autonomic dysreflexia (high blood pressure)	20%	62%
Pain	20%	54%
Spasticity	15%	46%
Getting hurt	5%	15%
I have experienced the following emotions since SCI that affect my sexuality/ From the perspective of a healthcare provider who works with men who have a SCI, men with SCI would report the following emotions experienced post-injury affect their sexuality:		
Frustration	80%	77%
Depression	55%	85%
Loneliness	50%	85%
Embarrassment	50%	92%
Exhaustion/ fatigue	50%	62%
Anger	45%	92%
Amazement	35%	15%
Pride	35%	31%
Anxiety	30%	70%
Mourning (sadness)	30%	62%
Shame	25%	70%
Negative sexual experiences after SCI/ From the perspective of a healthcare provider who works with men who have a SCI, men with SCI would report that negative sexual experiences post-injury:		
Lead to avoidance (decreased participation) in sexual activities	45%	45%

Decrease my confidence	35%	35%
Have a negative effect on my overall quality of life	25%	25%
Positive sexual experiences after SCI/ From the perspective of a healthcare provider who works with men who have a SCI, men with SCI would report that positive sexual experiences post-injury:		
Increase my confidence	65%	92%
Lead to increased participation in sexual activities	65%	85%
Have a positive effect on my overall quality of life	60%	92%
Help me accept my injury	40%	54%
Give me hope for the future	35%	70%

Appendix S: ***Information about Sex after SCI: Men versus Healthcare Provider Delphi Results***

	Percent Agreement	
	Men	**Healthcare Providers**
The best time to receive information about sex after SCI is/ From the perspective of a healthcare provider who works with men who have a SCI, men with SCI would report that the best time to receive information about sex after injury is:		
While in rehabilitation	75%	85%
Ongoing	65%	70%
0-6 months after injury	45%	38%
6-12 months after injury	40%	31%
Immediately after injury and again once you are back in the community	30%	38%
Immediately after injury	25%	7.5%
1-2 years after injury	20%	7.5%
More than 2 years after injury	20%	7.5%
I do not want to receive information about sex	15%	0%
I want to receive information about sex after SCI from/ From the perspective of a healthcare provider who works with men who have a SCI, men with SCI would report that they would like to receive information about sex after injury from:		
Relationship counsellor	65%	54%
Another man with SCI	65%	85%
Doctor	55%	92%
Physiotherapist	40%	62%
Psychologist	40%	46%
Nurse	35%	54%
Occupational therapist	25%	54%
I do not want to receive information about sex	0%	0%
I would like to receive information about sex after SCI in the following way(s)/ From the perspective of a healthcare provider who works with men who have a SCI, men with SCI would report that they would like to receive information about sex after injury in the following way(s):		
Conversation with healthcare provider	75%	77%
Conversation with another man with SCI	70%	77%
Internet	55%	62%
Video	50%	70%
Group discussion	45%	46%
Pamphlet	40%	70%
Book	30%	31%
I do not want to receive information about sex	5%	0%

Appendix T: ***Published Paper - Examining the Psychological and Emotional Experience of Sexuality for Men After Spinal Cord Injury***

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HEALTH PSYCHOLOGY | RESEARCH ARTICLE

Examining the psychological and emotional experience of sexuality for men after spinal cord injury

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Abstract: Sexual rehabilitation for men after spinal cord injury (SCI) has focused on physical challenges and has neglected psychosocial factors. Utilizing a descriptive phenomenological approach, the lived psychological experience of sexuality was described for six men (age 24–49) with complete or incomplete SCI (C4-T12; <1 year to 29 years post-injury) who participated in one in-depth, standardized, open-ended interview (68–101 minutes). Participants described the emergence of a new perspective of sexuality placing less emphasis on any one physical act and more importance on emotional factors. Understanding the evolving meaning of sexuality for men after SCI is imperative for delivering effective sexual health information.

Subjects: Rehabilitation Medicine; Disability; Chronic Diseases; Sexual and Reproductive Health

Keywords: male sexuality; sexual satisfaction; intimacy; sexual health; spinal cord injury

1. Introduction

Sexuality is a basic human need that is vital for achieving satisfaction with one's overall quality of life (QOL) (Reitz, Tobe, Knapp, & Schurch, 2004). Society has strong ideals of what sexuality is and who is

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Jacqueline Kathnelson, PhD Candidate, obtained her Bachelor of Kinesiology and Master's of Science from Brock University. She has studied at the University of British Columbia, and is currently a PhD Candidate in the Department of Kinesiology and Health Science at York University in Toronto, Canada. Jacqueline's research interests include a holistic view of sexuality for men and women after spinal cord injury with consideration of bladder incontinence and cardiovascular dysfunction. Her current research focuses on the psychological and emotional experience of sexuality for men after spinal cord injury.

PUBLIC INTEREST STATEMENT

This manuscript explores the psychological and emotional experience of sexuality for men after spinal cord injury. A spinal cord injury will often effect change to one's body, and consequently, the way sexuality is experienced is also changed. Research has been predominately focused on the physical aspects of sexuality, however, the men in this study revealed that the psychological and emotional aspects of sexuality were more important than the physical due to changes in function and sensation. This manuscript will contribute to a deeper and more holistic understanding of how men with spinal cord injury view and experience sexuality, and how these men describe the meaning of sexuality post-injury. This manuscript outlines the evolution of a new perspective of sexuality for these men which may be instrumental for researchers and health care providers to consider when developing and implementing relevant and successful sexual health education and rehabilitation programs.

allowed to participate. Sex is viewed by society as a privilege of the young, beautiful and non-disabled, thus suggesting that individuals with disabilities, including spinal cord injury (SCI) are not sexual (Sakellariou & Sawada, 2006). Individuals with SCI are told they must disregard their inherent sexual desires that are human in nature, and abandon that part of themselves (Herson, Hart, Gordon, & Rintala, 1999). However, sexual adjustment after SCI is not solely dependent on genital function or level of injury (Siösteen, Lundqvist, Blomstrand, Sullivan, & Sullivan, 1990). Despite changes in mobility and sensation, sexual desires may be unaltered and sexuality continues to be important to many individuals after SCI (Sakellariou & Sawada, 2006; Siösteen et al., 1990). Kreuter, Sullivan, and Siösteen (1996) suggest that sexuality is not synonymous with genital function, and that the emotional and sensual dimensions of sexuality may compensate for physical limitations resulting from SCI.

In terms of sexuality for men after SCI, literature has focused primarily on physical aspects of sexuality such as obtaining and maintaining an erection, and successful ejaculation. Emphasis has been placed on the measurement of these physical indicators of sexual performance (Sunilkumar, Boston, & Rajagopal, 2015), and the psychological aspects of sexuality have been largely neglected for men with SCI (Basson, Walter, & Stuart, 2003). Nevertheless, sexuality is multifaceted and due to changes in function and sensation, the psychosocial aspects may be more important than the physical factors for achieving satisfaction with sexual life in this population (Kreuter, Sullivan, & Siösteen, 1994; Siösteen et al., 1990). General anxiety, performance anxiety, negative self-concept, feeling sexually unattractive, emotional distress, fear of rejection, depression, feelings of sexual inadequacy, lack of confidence and self-doubt regarding sexuality after SCI may have a more profound negative affect on sexual adjustment than the actual genital dysfunction (Low & Tunku, 2000; Siösteen et al., 1990) and may lead to avoidance of sexual activities (Kreuter et al., 1996). Therefore, addressing the psychological and emotional concerns resulting from SCI, especially in the context of sexuality, may be just as important as physical rehabilitation (Giuliano et al., 2008). This study aimed to examine the lived psychological and emotional experience of sexuality for men after SCI.

2. Materials and methods

2.1. Phenomenology

An inductive and exploratory qualitative approach was employed. Utilizing Giorgi's descriptive phenomenological method (Giorgi, 2009), an in-depth examination of the experience of sexuality for men living with SCI was conducted to explore their lived experiences. The goal of this study was not to predict, but to receive information.

2.2. Participants and recruitment

Phenomenology requires the participants have personal, lived experience with the phenomenon under investigation (Patton, 2002), and recognizes that only certain individuals will be able to provide information that is useful and relevant for describing the phenomenon. Therefore, purposive sampling was used to select participants based on the information they would be able to provide (Carpenter & Suto, 2008). This resulted in detailed, information-rich descriptions of experiences from men who had firsthand knowledge of sexuality after SCI (Creswell, 2007). Phenomenological investigations generally involve a small number of participants (Carpenter & Suto, 2008; Polit & Hungler, 1995) and focus on meaning, richness and depth of the data that are uncovered rather than sample size (Liamputtong, 2009). Six participants took part in this study which falls within the recommended guidelines for this type of investigation (Patton, 2002; Polit & Hungler, 1995). Individuals were eligible to participate if they were male, between the ages of 18 and 50, living in Canada with a SCI of any level or classification and were able to communicate in English. Participants were recruited via posts on relevant social media platforms, by word of mouth and through support from Spinal Cord Injury Ontario.

2.3. Interviews

Pseudonyms were chosen by each of the men who participated in this study, and they were referred to by these names throughout the entirety of the investigation. Each participant

completed one confidential, in-depth telephone interview lasing between 68 and 101 minutes in length (mean time 81 minutes). Interviews followed a standardized, open-ended approach combined with interview guide approach (see Appendix A for complete interview guide) ensuring the same topics were addressed with each participant while also allowing for further investigation into new and relevant topics that arose but were not planned for or not anticipated (Patton, 2002). The main interview questions can be found in Table 1 and included the six types suggested by Michael Quinn Patton: demographic, experience/behavior, knowledge, sensory, feeling/emotion and opinion/value (Qualitative Research & Evaluative Methods, 3rd ed, 2002), and probing questions were used to delve deeper and obtain additional information regarding certain topic areas. Interviews were audio recorded using a Sony ICD-PX370 digital voice recorder and were transcribed verbatim. Field notes were recorded during each interview. Ethical approval was obtained from the York University Research Ethics Board and the Brock University Research Ethics Board.

2.4. Analysis

Data were analyzed by means of ongoing and constant comparison to determine how one transcript may convey a message about the others. This was achieved using Giorgi's method and adhered to the following procedure: transcription, read and jot, meaning units, first transformation, specific descriptions, general descriptions, revelatory phrases and emerging themes (Giorgi, 2009). Analysis began with unique, or within-case orientation where each transcript was examined as its own case. This was followed by a cross-case analysis and individual cases were compiled to examine the phenomenon across various contexts and relationships, and to uncover the prominent themes and patterns that emerged between them. Data were analyzed independently by two researchers and discussed until a consensus was met regarding emergent themes, and a reflective journal was kept throughout the process to track decisions (Carpenter & Suto, 2008). To stay close to the data, themes were supported by direct quotations from the participants' transcripts. The emerging themes represent the lived experiences and prominent ideas of these particular men regarding this particular phenomenon.

Table 1. Main interview questions

Question number	Main interview guide questions
1.	Can you start by telling me a little bit about yourself and your spinal cord injury?
2.	What is the meaning of sexuality to you?
3.	How has your spinal cord injury impacted your sexuality and/or sexual function?
4.	Describe a time after SCI when you felt sexually satisfied (or describe a situation that would make you feel sexually satisfied).
5.	How would you describe any body issues that you are concerned about when participating in, or thinking about participating in sexual activities?
6.	How has your spinal cord injury affected the way you see yourself? How has this affected your sexuality?
7.	Tell me a story about a time or situation when your SCI affected your sexual life.
8.	As you talk about and reflect on your sexual life after spinal cord injury, what types of feelings and emotions are you experiencing?
9.	What resources have you used or accessed (books, pamphlets, videos, support groups, etc.) to help with adjusting to your sexual life (sexuality, sexual function) after SCI?
10.	Is there anything that we didn't talk about today that you would like to discuss now, or is there anything that you would like to add to our conversation?

3. Results

Six men with complete or incomplete SCI (C4-T12) between the ages of age 24 and 49 participated in this study. Participants were <1 year to 29 years post-injury. All of the men identified as heterosexual. Four of the men were married, one was in a relationship and one was divorced. Three of the six men had children. Of these men, two had children prior to their injury and one had children after his injury. Table 2 outlines demographic and interview characteristics for each participant.

3.1. Themes

The men in this study acknowledged stereotypes and societal beliefs pertaining to sexuality, masculinity, disability and attractiveness and recognized that as a result of their SCI, they no longer conformed these norms. The men expressed the importance of adapting their own beliefs regarding these topics in order to find acceptance of themselves in *"a world that is not all that accepting." -Will*

Elliott: Definitely I've fallen into stereotypes of what disability and sexuality were like until I started to investigate it more and realized that they're not entirely true. Every part of my body and the way in which society views the norms of what a body should look like. I think I'm constantly going back to it thinking that there is something inherently wrong with my body. ... facilitating an erection can be tricky and it's kind of the main part of many peoples' view on what sex should look like. So if you don't have a really great erection then obviously you're kind of failing in one very important part of what many partners find very important.

3.1.1. Changing perspective of sexuality

When asked to describe the meaning of sexuality, all of the men in this study described feelings of intimacy and connection with themselves and/or their partner on an emotional level. The men stated that being physical and/or having penetrative sexual intercourse may play a role in sexuality, but revealed that the physical aspects of sexuality were "just a tiny little part of it."

Table 2. Participant and interview characteristics

Participant	"Joe"	"Elliott"	"Will"	"Steve"	"Paul"	"Peter"
Interview Length	81 min	101 min	83 min	67 min	86 min	68 min
Age	24	32	45	49	49	47
Injury	C7 Incomplete	C4 Incomplete	T9 Complete	C4/C5 Incomplete	T12 Incomplete	T6 Complete
Years Post-Injury	6 years	15 years	28 years	29 years	7 years	7 months
Sexual Orientat-ion	Hetero-sexual	Hetero-sexual	Hetero-sexual	Hetero-sexual	Hetero-sexual	Hetero-sexual
Relation-ship Status (current)	In a relation-ship	Married	Married	Married	Divorced	Married
Relation-ship Status (at injury)	In a relation-ship	In a relation-ship	Single	In a relation-ship	Married	Married
Participat-ion in Sexual Activities Prior to Injury	No	Yes	Yes	Yes	Yes	Yes
Participat-ion in Sexual Activities Post-Injury	Yes	Yes	Yes	Yes	Yes	No

-Paul

Joe: Meaning of sexuality? I guess how one feels or expresses their intimate feelings. … it's not all about sex at all. For me it's more emotional.

Will: [Sexuality is] the intimacy between two people. … it's not defined by one particular act [intercourse]. Sexuality is everything from the intimacy between two people, their interactions, the different ways that they arouse each other and the different ways that they inspire each other in those intimate moments.

Steve: [Sexuality is] being connected with yourself emotionally and physically. And sexuality is also about being connected with your partner in that same emotional type of way. Not just in the physical sense.

This portrayal of sexuality differs from the description of sexuality these men thought they would have provided in the past. Prior to SCI, the men thought of sex and sexuality in a physical sense with emphasis on penetration and intercourse. They referred to this as the "traditional" view of sexuality. Post-injury, physical factors became less important due to decreased sensation and decreased ability to trigger an erection or successful ejaculation, as well as decreased physical function and mobility to perform various sexual activities. The men explained that sex cannot be defined the same way it was prior to injury, and that the meaning of sexuality was an evolving concept that changed and expanded over time and with new experiences.

Will: It's a long road getting to that point where you get past what would be considered a traditional method [of sex], however you want to define it. It becomes about things that you may not have realized were quite as important before. It's something that yes, you have to define it in a different way, you don't really have a choice. You can't try to define it [sexuality] by the same way it was pre-injury.

Elliott: I think before my spinal cord injury, the way I would think of sexuality was penetration. And that was basically it. I just wasn't really interested in a whole lot of stuff other than that. Right now, I'm more leaning towards the non-penetration side of a variety of sexual activities.

Will: It [SCI] took the focus off of the one traditional act that everyone comes to think about when it comes to sexuality, and moved it to other places, and thinking about it in other ways. And sometimes it actually doesn't have to do with any one act or anything. It definitely becomes more emotional.

As the men let go of the idea of sex as a purely physical, penetrative experience, they became more appreciative of the psychological and emotional side of their sexual relationships, and experienced sexuality in a new way. One participant explained that he was able to reach a deeper level of intimacy which he felt he would have been unattainable without his injury. He supposed the focus on physical factors of an able-bodied person would actually inhibit their ability to reach an understanding of intimacy on that level. In his opinion, sexuality was more fulfilling within this perspective than it was prior to injury.

Steve: Sex is way different because I focused solely on genitalia [before SCI]. It took a while at the beginning because you think of sex from a physical standpoint. You don't think from an emotional standpoint. It [SCI] just opened my mind to a whole different level of sexuality because guys are normally not taught to be emotional in any way or in contact with your own sexuality that way. And it's much more fulfilling in my opinion to be connected with your partner emotionally than it is just the physical aspect. I honestly probably don't think [I would have gotten to this level of sexual fulfilment without SCI] because I would have been concentrating so much on the physical aspect of it. I don't know if that would have gotten in the way of understanding that level of intimacy. The physical aspect of feeling your genitalia and you know, wanting to have that physical release is actually in the way of your emotions. You really have to look at it from a different perspective. And you can't look at it from your typical male perspective … it's not just about getting off. It's about being

connected. And it [SCI] really taught me that. Because that physical release, you have to find it from a different avenue of connection. And it's more fulfilling being this way than it is being the other way.

Men who had not embraced this new perspective of sexuality struggled to find satisfaction within the traditional framework of sexuality, and in some cases, this led to decreased interest and participation in sexual activities. When asked to describe a time since his injury when he felt sexually satisfied, the most recently injured participant (<1 year post-injury) who was focused on recovery and regaining "normal" function and sensation, reported that he was unable think of a time when he had been sexually satisfied post-injury. This is in contrast with the men who had embraced the new perspective of sexuality, focusing less on physical function and sensation, and placing more emphasis on intimacy and emotional connection.

Furthermore, as a result of being unable to *feel* the body or pleasurable sexual sensations, including climax, in the same way they did prior to injury, all of the men in this study reported that they now placed more emphasis on their partner's sexual satisfaction. Many of the men stated that a great deal of their own sexual satisfaction came from their partners' satisfaction, and through their partner, they, themselves were able to feel satisfied in a sexual sense. For the majority of these men, this differed from their perspective of sexuality prior to injury as they had tended to be more concerned about themselves in their past sexual situations.

Elliott: [Before SCI] I was just basically thinking about myself a lot of the time. And I think after my spinal cord injury I've also learned that your partner is very, very important to think about. And you can have a positive experience from your partner's reaction as well. [Sex] definitely doesn't feel the same as what it used to feel like, so I think it's very difficult for me to only focus on myself when it's very difficult for me to get to that point [climax] so I tend to focus I think more so on my partner.

Steve: That's how I get pleasure out of it now. Pleasuring my partner. That's what gets me excited. That's where I get my enjoyment from. It's that my partner is being pleasured.

Generally speaking, participants conveyed a continued importance of sexuality in their lives post-injury. The men explained that satisfaction with their sexual lives was necessary for improving other physical and psychological health issues, and that sexual satisfaction was vital for improving their outlook on life and overall QOL.

Elliott: I definitely know that I am a little bit more frustrated because that part of my life [sexual] hasn't been as adequate or what I was hoping it would be. It definitely makes my mood a lot worse. … my thoughts about myself, and just life in general is not always the greatest, but they probably would be if my sexuality was a little bit more positive.

3.1.2. Changing perspectives of masculinity

Participants in the current investigation admitted to taking part in, or at least being aware of, society's beliefs about the meaning of masculinity which they characterized using terms such as *strength, dominance* and *sexual conquests*. The men also acknowledged that SCI affects many of the traditional measures of masculinity in both activities of daily living as well as in a sexual sense. Again, the men in this study were able to expand their views of masculinity and redefine the concept. By placing more emphasis on the strength required to allow others to support them, the nobility in being there to support those close to them, the strength in being vulnerable, showing emotions and exposing one's true self rather than focusing on strength in the physical sense that is often associated with masculinity, there was acceptance that they were no less of a man as a result of the injury. It was also noted that sex can be experienced and enjoyed in many ways, and having the man play the dominant role in a sexual setting is not the only approach.

Elliott: … before my injury [I had] very specific stereotypes in my head where the man was supposed to be the strong one and the man was supposed to be the dominant persona, especially like in a sexual sense. Now, after my injury, I really can't be the physical, dominating [person] in

a sexual relationship and it plays into the way I actually feel about sexuality. And I don't think there is any general way to look at how a man or a woman should act in this situation. I think everyone enjoys [sexuality] in a bunch of different ways.

Will: I don't believe in the old toxic masculinity view of things. I don't judge myself as a man by my conquests. To me, being a man is just simply what you are to your friends and family, to the people that you care about. It's about being there to support others, it's about being there to let them support me if and when I need it. Now that probably has changed quite a bit from prior to the injury because, yes, I did definitely judge myself by other people's achievements, how many women had I dated etc. Yeah, I could have very much fallen into that category. But these days I don't judge myself as a man by that aspect at all. I do find myself occasionally falling into that trap because things [penis/body] don't work as the average man thinks they should. That does occasionally get you a little depressed, but I do try to get myself out of that by realizing it hasn't changed who I am as a person.

Steve: 'Oh suck it up, don't cry, men don't cry.' Yeah, we do, and you should. And you should express that. And I find that I'm more of an emotional person now. And that's a real man. The real man is someone who can show their emotions, not just anger and other things.

3.1.3. Changing perspective of disability

Spinal cord injury affects how an individual is viewed within society, and the men suggested this is because SCI is a visible disability. The men felt the injury was the first thing people saw when they looked at them and suspected that some people may not be comfortable interacting with them because of the injury. The men have felt misunderstood when people assumed they must have a mental disability as well as a physical limitation. They have felt looked at as a patient more than a person, viewed as a science project, and they have felt that people look at them with pity. The men explained that for some people, the SCI is not something they can look past. This is challenging when meeting new people in general, and also when trying to meet a new potential sexual partner. The men in this study described the importance of finding a partner who was willing to look past the injury, and who was open to getting to know them as a person.

Will: I recognize and acknowledge the fact that when you're meeting new people for the first time, the chair is the first thing that many of them will see. Some people can't get passed it. It's [SCI] always there in one way or another. People are always wondering how they can help me, and if I need help.

Joe: You always feel like people are looking at you with pity, like they feel bad for you. And it's sometimes difficult to get them past that point. You always feel like they're looking at you as sort of a poor person that has to be looked after. So, a lot of people have this misconception that when I say wheelchair people think mental disability or that I can't do anything below my head, stuff like that. It can be tough. You can't really blame them for that. They just don't have any experience previously with people in wheelchairs.

Joe: Being in the hospital, I've been looked at as a patient more than a person for three years. Everybody would look at me as a person with a spinal cord injury, like, 'he's just a patient. He's a science project.' So, once I was able to meet someone who looked at me as a person rather than a patient, that just made me feel completely so much better.

Steve: ... those online dating sites. I was trying to go out there with a generic profile, so you get all your physical attributes and they call you and then [after finding out you have a SCI] they're like, 'oh, yeah never mind ... '

3.1.4. Changing perspective of attractiveness

Society has beliefs about what an ideal body is supposed to look like, and the body of a man living with SCI may not encompass that vision. Participants in this study revealed that after their injury, they felt as though no one would find them attractive. The men questioned their own appeal to another person and felt they would have to settle in terms of the partner they would end up with. This led to an enhanced fear

of rejection and avoidance of approaching new people, thereby resulting in feelings of loneliness and depression.

Elliott: *At that point I had been fairly certain that like, like no one would find me attractive because of my disability and because of my spinal cord injury. I just kind of assumed that wasn't something that was going to happen.*

Joe: *It takes me back a little bit to the beginning of my injury when I thought everything was over and that I'd never be able to find anyone that's attracted to me. [At first] you just don't feel like it's going to be possible to find a partner or that you'd have to lower your standards to the point where you're not even attracted to the person. It triggered depression. There are other parts of the injury that cause that too, but mainly it was a feeling of loneliness.*

Elliott: *I just didn't really feel comfortable approaching anyone. It's definitely something that's very difficult for someone with disabilities. I think there is constantly a fear of rejection. I think it's a lot more now than it was before my injury. It still would be just very, very difficult for me to actively engage in a relationship because of self-doubt.*

One participant described a specific situation where he felt his SCI affected the way women viewed him and his level of attractiveness as a potential partner:

Steve: *When I sit in my car, you can't tell I'm in a wheelchair. I'm a good-looking guy, and all they can see is my face and my smile. I get out of my car, and they turn their head away. I'm the same guy you just looked at, like looks-wise, but now I'm in a wheelchair. So, what's the difference?*

Men described specific body image issues they experienced as a result of SCI which included a loss of muscle mass, a larger stomach, pressure sores, spasticity, restrictions on the type of clothing they could wear, bladder and bowel issues, always being in a seated position and having a flaccid penis. The men compared their current bodies to their bodies prior to injury, and described the difficulty and frustration in not being able to do anything about it. Due to the fact that they could not be as physically active as they were prior to injury and could not engage certain muscles to work, they expressed a sense of hopelessness.

Steve: *Now I have a quad gut (larger stomach due to inability to engage core muscles) and my arms are skinny my legs are skinny. Like I said, I was an athlete. I was fit. That is hard for body image.*

Will: *I've got the tummy, my [legs] have withered, and unfortunately because of the nature of the injury, with the loss of strength in muscle tone of my abdomen there's a lot of weight. It's not even weight, it's more just flab that has appeared just because you can't do proper exercises in that region, the muscles don't work all that much and I've gained myself a belly.*

Changes to body image also enhanced their fear of rejection by a potential partner and heightened avoidance behavior.

Elliott: *Just initiating any type of [sexual] activity with anyone else was terrifying and I just didn't really want to get into it. I just found a variety of parts of my body unattractive and I felt that if I got into a situation with anyone else, they would also find me unattractive.*

Joe: *I was at my lowest point in confidence. Confidence in myself. Feeling that people wouldn't be attracted to me, or confidence in approaching people, or you know, so-called 'making a move' or anything like that really.*

One participant went on to discuss how these issues with body image affected his feelings about himself, his confidence, his self-esteem and how these insecurities caused him to fall back into the negative self-thoughts he had been able to overcome prior to his injury. Ultimately, he was led to question his appeal to potential partners.

Will: *It's hard not to judge myself, and that affects your view of yourself. I thought I had gotten over them [my insecurities] before the injury took place because I was more confident with myself. I became successful to a degree in life, and then this happens, and then you start questioning everything again. When you look at yourself, and unfortunately because you're in a seated position*

all the time, it makes things look that much worse than if you were able to get into a standing position. It reduces what you see as your own appeal. When you layer that on top of the fact that things don't work [penis], umm, you start to, you can't help but question what your own appeal is. What would it be that would bring people to you to see you that way [as a potential sexual partner]?

Participants believed they were doubly disadvantaged as consequences resulting from SCI left them feeling unattractive, as well as feeling disabled in the sense that the body, and specifically the penis, did not function the way they believed it should. While able-bodied men may feel insecure about the size of their penis due to society's obsession with its appearance, men with SCI may feel an added insecurity in this regard due to an inability to achieve erection. When participating in sexuality activities, if the penis is flaccid, it may appear smaller than it would if it were erect adding another dimension of concern for these men.

Joe: With men obviously there's always an obsession with, everyone constantly talking about the size of your penis. That's the body image thing for men. There is always a nervousness about that, even so like it may not be small or whatever, but when you're not using it sexually all the time or getting erections all the time without medication they usually shorten because you're not exercising that stretching right? So that's definitely a concern, and always is.

Participants acknowledged the high probability that all men, able-bodied or not, are likely to have concerns with body image. However, they explained that men with SCI have to deal with all the concerns any man would have to deal with, as well as an added layer of concerns that are directly related to the injury. Two participants explained that SCI had escalated the negative body feelings they experienced prior to injury, with the injury making them more intense.

Joe: I would say [men with SCI have] the same body issues [as able-bodied men], probably a little bit worse because you're sitting down all the time. And you're limited in what kind of clothing you can wear. Or I'm limited, by like, pressure sores, so I can't wear jeans. Umm, yeah, it's a different set of body image issues but I think everyone has them to an extent. Able-body or not.

Elliott: Even before my injury I always had a hard time with various parts of my body. But they did emphasize after my injury. [SCI] definitely made a lot of my body perceptions a lot worse than they were before.

Similar to the concepts of sexuality, masculinity and disability described above, one participant suggested that people need to change their views of what they think they are looking for in a partner, expanding beyond the physical and reaching into the more meaningful, deeper connections. He explained that people put a lot of emphasis on physical attributes, but that personality and connection with a virtuous person are more important than their superficial traits.

Steve: ... people who want to be with you want to be with you regardless. So when you realize that, you are more confident. Sure, there might not be as many people you come across that want to give you that chance, but then you weed out the bad people. What does 6 foot 3 have to do with anything? Nothing. Find a guy that treats you nice. Find a guy that will be kind. And will listen. Like, a guy that has six pack abs and huge muscles, and biceps, and everything like that, you really think he's deep? Do you really think he's gonna care about your needs? Some guys might. I'm generalizing again. Some guys might, but few and far between. Find connection, and you'll be so much more fulfilled. If people would realize that, they would be so much happier.

4. Discussion

Sexuality and sexual function are of top priority for individuals living with SCI (Anderson, 2004) and play an important role in their overall rehabilitation (Sheel, Krassioukov, Inglis, & Elliott, 2005). Literature suggests that over 80% of individuals with SCI feel that their injury has altered their sexual sense of self, and that improvements to sexual function would improve their overall QOL (Anderson, Borisoff, Johnson, Steins, & Elliott, 2007). This is consistent with the present findings as

the men in this study generally felt that if they improved their sexual lives, they would improve their mood, they would feel happier and the quality of their lives would be better overall.

The top two areas of research for men regarding sexuality after SCI are erectile dysfunction and ejaculatory dysfunction (Anderson et al., 2007). Although effective treatments for erectile dysfunction and anejaculation exist, the psychological and emotional consequences of SCI on sexuality for men remain understudied (Dahlberg, Alaranta, Kautiainen, & Kotila, 2007). Sexuality is a complex physical and psychological phenomenon, and through a description of their own lived experiences, participants in this study identified an evolving meaning of sexuality in which psychosocial factors were vital to increasing sexual satisfaction. Participants generally, but to differing degrees, described the emergence of a new perspective on sexuality placing less emphasis on physical factors, specifically penetration, and more importance on psychological factors including intimacy, connectedness and emotional closeness with their partner. Men who reported embracing this perspective of sexuality reported a deeper and superior sexual experience and level of intimacy, some even more so than prior to injury, whereas the participant who had not adopted this perspective reported lower levels of sexual interest and satisfaction. This is consistent with a previous study of 134 able-bodied individuals that found greater levels of intimacy were linked to higher levels of sexual desire (van Lankveld, Jacobs, Thewissen, Dewitte, & Verboon, 2018). Furthermore, Štulhofer, Ferreira, and Landripet (2014) that found sexual satisfaction was contingent on intimacy, and similarly, a study by Pascoal, Narcisco, and Pereira (2013) found emotional intimacy to be the best predictor of sexual satisfaction in individuals with sexual arousal issues (Pascoal et al., 2013).

Masculinity was the second emerging theme and is a social construct that is closely linked to sexuality. Its clearly defined expectations may have a detrimental effect on men after SCI (Esmail, Darry, Waiter, & Knupp, 2010). Boys are taught the possession, size and use of their genitals, as well as initiating sexual activity and possessing a high sexual drive are indicators of manhood (Burns, High, Boyd, & Hill, 2009). Masculinity has been described in the literature, and by the men in this study, using words such as physical, athletic, assertive, breadwinner, dominant and sexual prowess, all of which may be affected by erectile dysfunctions and other physical limitations resulting from SCI. As a result, appropriate gender roles and sexual identity may be disrupted (Sakellariou & Sawada, 2006) making it necessary for the men in this study to alter their perspectives on the meaning of masculinity. Men focused on non-physical strengths, specifically the strength that comes from being a good person who is in touch with their feelings and emotions and who supports, and is supported by, those around him to represent the character of a "*real man*."

The third theme involved perspectives on disability. The men revealed that they often felt as though people saw only the disability when they looked at them and recognized the injury was not something that everyone would be able to move past. Participants with SCI have questioned whether the attention they received from others was out of curiosity about the disability and pity, or because of interest in them as a person. In most cases, participants assumed it was the former (Potgieter & Khan, 2005). Many myths exist about people who live with a disability, and due to a general ignorance about what it means to live with SCI, people may feel uncomfortable interacting with this population and may also have an assumption that they are asexual (Potgieter & Khan, 2005). Working to educate society about what it means to live with a SCI may improve social opportunities to engage in sexual relationships post-injury.

The final theme considered physical attractiveness. An ideal body may be thought of as one that stands, and for a man, it may also include a body that is strong, lean, muscular and athletic (Blond, 2008). These ideas are reinforced in society where exposure to the male body in its ideal form and as a sexual object is abundant (Blond, 2008), making it difficult for men with a disability to escape this perspective. Blond (2008) found that exposure to idealized male bodies in advertisements and other forms of popular culture had a significant negative impact on body satisfaction, specifically for those with lower levels of body satisfaction which may include those living with a disability.

Men with disabilities are taught that their bodies are unattractive because they do not conform to the socially accepted standards of an ideal male body (Potgieter & Khan, 2005), and the men in this study were aware of the ways in which their bodies deviated from this. Physical consequences of SCI described in this study included weight gain, a larger stomach, muscle atrophy, spasticity, pressure sores, flaccid penis, being in a seated position, not being able to wear certain types of clothing and issues with the bladder and bowel. As a result, the men felt unattractive and questioned their own appeal to a potential partner. Consistent with work by Potgieter and Khan (2005), the men experienced negative emotions including loneliness and depression as a result of avoiding opportunities to meet new potential partners due to a heightened fear of rejection.

Addressing the issues identified through this investigation may lead to improvements in the lived sexual experiences for men after SCI. Suggestions include educating healthcare providers on the changed perspective of sexuality for this population so that sexual education may be consistent with the interests and priorities of the patient. Healthcare providers should be aware of the stigmas surrounding sexuality and disability, as well as their own biases regarding the topic which may influence the information they provide, and which patients they choose to provide this information to. The findings of this study highlight and further support a need for the use of a biopsychosocial approach when addressing sexuality in SCI rehabilitation (Elliott, Hocaloski, & Carlson, 2017; Pieters, Kedde, & Bnder, 2018), allowing for holistic consideration of this multifaceted and complex phenomenon, integrating both the physical and psychological/emotional aspects of sexuality.

This study recognizes its possible limitations. Participants varied in terms of injury level and classification which provided a broad view of the issues that exist for this population. While this approach was valuable for capturing the core experiences of this phenomenon across contexts and identifying factors of particular interest (Patton, 2002), it is possible that the severity of injury may affect one's perspectives of sexuality. However, the themes presented in this paper represent broad social constructs and there appeared to be no notable differences based on injury level or classification. Perspectives were influenced more by time since injury and past experiences (positive or negative). Present findings describe the lived experiences of these particular men at this particular point in time and may not be generalizable to larger populations or other instances in time. Interviews were conducted by the primary researcher who is female, and it may be challenging for men to be forthcoming with information about their sexuality with a researcher of the opposite sex. However, it has been reported that men are equally, if not more likely, to reveal concerns related to body image with a female researcher (Yager, Diedrichs, & Drummond, 2013) and that a female interviewer is generally preferred. Possible explanations may be related to social norms and expectations that women would naturally be more sympathetic (Pollner, 1998) and less critical (Derlega, Winstead, Wong, & Hunter, 1985). Additionally, all of the participants in this study identified as heterosexual and the voices of these particular men may not represent those who identify with other orientations. Future work should consider other sexual preferences.

Men disclosed they had been challenged with overcoming the stereotypes assigned to them by society, as well as their own pre-injury ideas regarding the constructs of sexuality, masculinity, disability and attractiveness. These constructs play a role in one's overall sexual experience, and Potgieter and Khan (2005) concluded that socially constructed attitudes seemed to limit opportunities to express sexuality for individuals living with SCI more than their disability. Men with SCI may be aware of their deviations from societal norms and may benefit from learning to "reject the inflexible, discriminatory conventions rather than themselves" (Potgieter & Khan, 2005). The men in this study developed an adapted understanding of four dominant societal beliefs, moving beyond traditional definitions and embracing new and expanded meanings that were more consistent with life after SCI.

An updated and holistic understanding of how men with SCI describe sexuality is important for the development of relevant information and effective interventions that may have a positive impact on their sexual experiences and contribute to an improved overall QOL.

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Appendices
Appendix A

Interview Guide

Hello and thank you for speaking with me today.

This study involves a demographic questionnaire and a 1 to 1.5 hour in-depth interview. During the interview, we will be discussing sexuality after spinal cord injury. As we talk about sexuality and sexual function, I want you to know that when I use these terms I am referring to anything from the emotional intimacy experienced with a partner to the actual act of sexual intercourse, and everything in between unless specified otherwise.

Your interview will be audio recorded and transcribed verbatim. The audio recording will be used during the analysis process. I will also be taking some notes during the interview to record any information that stands out to me, or topics that I may want to come back to later in the interview. You may look over these notes at the end of the interview if you request to do so.

There are no right or wrong answers to any of the questions that I ask you today. I am here to learn about your own personal thoughts and experiences. During the interview, you may choose not to answer any question(s) that make you uncomfortable, or to terminate your interview at any time for any reason with no consequences whatsoever. I have provided some resources in your information-consent letter of organizations that you can contact should our discussion today evoke any feelings of distress. The information you provide will be kept confidential, and we will be using a pseudonym from this point forward to protect your identity. Can you please think of a name other than your own that you would like to be referred to throughout the remainder of this study?

Do you have any other questions before we begin the interview?

Phenomenological Question: What is the experience of sexuality for men after spinal cord injury?

Interview Questions:

(1) Can you start by telling me a little bit about yourself and your spinal cord injury?
(Demographic/Background Question)

Probe questions:

(a) How would you describe yourself (personality, character, interests ...)?
(b) Can you tell me a little bit about your injury (level, classification, circumstances, interpretation of impact on life, generally ...)?
(c) Tell me about your current relationship status (if separated/divorced what do you think caused the relationship to end? If single is that by preference? Why do you think you are single? If in a relationship that started prior to the injury how has the relationship changed since the injury)?
(d) Prior to your injury, did you see yourself as a married person with children? And now?
(e) What challenges do you face when establishing new relationships, both in friendship and romantic contexts?
(f) How is, or how do you think, dating is different for someone with a SCI? (methods of meeting/dating, additional complications/challenges, qualities you look for in a partner before/after injury)?

(2) What is the meaning of sexuality to you?
(Opinion/Value Question)

Probe Questions:

(a) How is the meaning of sexuality different before versus after your injury?
(b) How did your SCI change or expand what sexuality means to you?
(c) What experiences led to these beliefs (both before and after SCI)? (society?)
(d) What role does sexuality play in your life?

(3) How has your spinal cord injury impacted your sexuality and/or sexual function?

(Experience/Behavior Question)

Probe Questions:

(a) Did you participate in sexual activities prior to your injury (the term "sexual activities" refers to a broad range of activities and does not necessarily mean sexual intercourse)?

> Any sexual challenges prior to SCI (meaning **not** related to SCI; examples:

medical comorbidity, sexual abuse, emotional issues, performance related issues)

> Can we talk about what was going on at that time?

(Sexual history assessment questions to separate challenges resulting from SCI from those not related to SCI)

(b) Have you participated in sexual activities since your injury?

> What types of sexual activities? How do these activities differ from the activ-ities you preferred prior to your injury?

> More emphasis on psychological/emotional factors? Closeness?

> How long after SCI before you began participating in sexual activities? Why?

(c) Has your desire or interest in sexuality changed since the injury?
(d) Have there been changes in erection (obtaining, sustaining)?
(e) Have there been changes in your ability to reach orgasm?
(f) How have any of the changes described affected your sexual life? (ex. increased/decreased creativity/sexual exploration, development of new erogenous zones, use of sexual aids: oral medications, topical agents, injections, devices, implants, etc)

(4) Describe a time, after SCI, when you felt sexually satisfied (or describe a situation that would make you feel sexually satisfied)

(Opinion/Value Question)

Probe Questions:

(a) What made it satisfying for you?
(b) Under what conditions would you consider yourself sexually satisfied? (physical? emotional? psychological?)
(c) How satisfied are you with your sexual life?

(5) How would you describe any body issues that you are concerned about when participating in, or thinking about participating in sexual activities?

(Sensory Question)

Probe Questions:

(a) What changes regarding your body have affected your sexual life? (ie: body image, bladder, bowel, spasticity, pain, fatigue, decreased mobility, decreased sensation, skin issues, autonomic dysreflexia ...)
(b) To what extent are these issues a concern for you?
(c) To what extent does your fear of these body issues affect your sexuality? to engaging in sexual activities to account for these issues/concerns?
(d) What about preparation for sexual activities? What precautions do you take prior
(e) How does it make you feel when you have to discuss these concerns with your partner? How does this affect the sexual experience?

(f) How are the concerns you have similar or different to the concerns of your partner(s)?
(g) How much disclosure do you feel is appropriate when discussing sex after SCI with a new potential partner?

(6) How has your spinal cord injury affected the way you see yourself? How has this affected

(Opinion/Value Question)

Probe Questions:

(a) How has your SCI affected your self-esteem? Body-esteem? Body image? Sexual confidence? Self confidence?
(b) How do you feel about, or how have you been affected by the societal obsession with "ideal bodies?" (social pressures, attractiveness, non-typical bodies)
(c) How do you think this is different for women with SCI than it is for men with SCI?

(7) Tell me a story about a time or situation when your SCI affected your sexual life.

(Opinion/Value Question)

Probe Questions:

(a) Positive or negative experience?
(b) Describe the worst possible case scenario that has either happened, or could happen to you related to sex after SCI.
(c) Describe the best possible case scenario that has either happened, or could happen to you related to sex after SCI.

(8) As you talk about and reflect on your sexual life after spinal cord injury, what types of feelings and emotions are you experiencing?

(Feeling/Emotion Question)

Probe Questions:

(h) Frustration? Disappointment? Sadness? Longing? Pride? Amazement?
(i) What types of feelings and emotions have you experienced in your sexual relationships?

(9) What resources have you used or accessed (books, pamphlets, videos, support groups) to help with sexual adjustment (sexuality, sexual function) after SCI?

(Knowledge Question)

Probe Questions:

(a) How useful are these resources?
(b) Where did you get them?
(c) When did you access them?
(d) How much information was provided to you regarding sexuality after SCI after your injury?
(e) What was your initial reaction to this information?
(f) What resources are you aware of that you have not used or accessed?
(g) Is the amount of information that is available adequate? What is missing?
(h) How much would you say these resources are targeted towards men? Women?
(i) Do you think there is an optimal time to begin talking about sexuality?
(j) Who would be the ideal person to talk to you about sexual issues after SCI (health care professional, peer, male, female, SCI, able-bodied)?
(k) To what extent are your Doctors/health care providers comfortable discussing sexual function with you?
(l) How comfortable were you asking health care providers questions about your sexual functioning/interventions to help with sexual functioning?

> What were some of the barriers to this conversation?

> What were some of the facilitators to this conversation?

(m) To what extent are your Doctors/health care providers knowledgable on the topic of male sexual function after SCI?

(n) Do you think there is a health profession that is more suited than others to address this?

(10) Is there anything that we didn't talk about today that you would like to discuss now, or is there anything that you would like to add to our conversation?

(Final Question)

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Appendix U: *Published Paper - Supporting Sexual Adjustment from the Perspective of Men Living with Spinal Cord Injury*

Spinal Cord
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ISCoS The International Spinal Cord Society

ARTICLE

Supporting sexual adjustment from the perspective of men living with spinal cord injury

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Abstract

Study design Descriptive phenomenological approach.

Objectives This study explored the lived experience of sexuality for men after spinal cord injury (SCI) and described the current state of tools and resources available to assist with sexual adjustment from the perspective of men living with SCI.

Setting Men living in the community in Ontario, Canada.

Methods Six men (age 24–49 years) with complete or incomplete SCI (C4-T12; <1–29 years post injury) participated in one individual, in-depth, standardized, open-ended interview (68–101 min). Analysis was conducted using Giorgi's method, and involved within case analysis followed by cross-case analysis.

Results All participants reported that resources available to support sexual adjustment after SCI were inadequate, and the majority of men felt their healthcare providers lacked knowledge regarding, and comfort discussing sexuality after SCI. Men reported sexuality was not a priority of the rehabilitation centers and felt that healthcare providers did not understand the importance of addressing sexuality. Existing resources were described as too clinical and not necessarily relevant given changes in sensation and mobility post injury. Participants provided recommendations for the effective delivery of relevant sexual education information.

Conclusions To improve quality of life for men after SCI, suitable resources must be available to support sexual rehabilitation post injury. Future research should focus on developing strategies to facilitate discussions about sexuality between individuals with SCI and healthcare providers, and on developing resources that are effective and relevant for these men.

Introduction

More than 86,000 people in Canada live with a spinal cord injury (SCI), half of which reside in the province of Ontario [1, 2]. While SCI will affect many body functions and sensations, an SCI does not eliminate sexual feelings or the need for physical and emotional sexual intimacy [3]. Sexuality and quality of life (QOL) are interwoven and reinforce one another, and an active and satisfying sexual life after SCI is associated with improvements in overall adjustment and QOL [4, 5]. A study by Anderson et al. [6] found that 83.2% of participants felt their SCI had altered their sexual sense of self, and 82.9% felt that improving sexual function was important for improving QOL. Despite the importance of sexual health and sexual education for individuals after SCI, there is an unmet need for sexual rehabilitation information, as well as numerous challenges for patient-provider discussions regarding sexuality [7, 8]. All of the participants in a study by Basson et al. [9] felt that they had received inadequate guidance regarding sexuality from their healthcare providers. Patients and healthcare providers alike have reported difficulties regarding sexual education for individuals with disabilities. Patients reported that healthcare providers lacked knowledge when it came to sexuality for people with disabilities and felt their healthcare providers were too shy to have the discussion with them [7]. From the healthcare provider perspective, barriers included

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a lack of time, lack of knowledge, lack of clarity regarding whose job it was to discuss topics of sexuality, their own attitudes about sexuality, and the patient's lack of readiness to discuss sexuality [10, 11].

Furthermore, existing resources have predominantly focused on the physical aspects of sexuality including erectile dysfunction and ejaculatory dysfunction [6]. However, recent work suggests that due to changes in the body resulting from SCI, men may adopt a new perspective on sexuality placing less emphasis on those physical factors and more importance on psychological and emotional components of sexuality including connection and intimacy with a partner and exploration of novel ways to experience sexuality beyond the traditional view of sex as a purely penetrative experience [12]. This study explored the lived experience of sexuality for men after SCI and described the current state of tools and resources available to assist with sexual adjustment from the perspective of men living with SCI (Tables 1 and 2).

Methods

Data for this manuscript were collected as part of a larger study examining the lived sexual experiences for men after SCI. A paper has recently been published from that data which discussed the evolving meaning of sexuality for men after SCI [12]. The present paper will report the health services information that was uncovered during that investigation.

Table 1 Demographic and injury characteristics.

Participant	Age group	Injury level/ classification	Time post injury
"Joe"	21–25 years	C7 incomplete	6–10 years
"Elliott"	31–35 years	C4 incomplete	11–15 years
"Will"	46–50 years	T9 complete	26–30 years
"Steve"	46–50 years	C4/C5 incomplete	26–30 years
"Paul"	46–50 years	T12 incomplete	6–10 years
"Peter"	46–50 years	T6 complete	<1 year

Using Giorgi's descriptive, phenomenological approach [13], the lived experience of sexuality for men with SCI was explored. Phenomenological studies typically employ a small number of participants that allow for a deep and detailed exploration of the topic under investigation [14]. A minimum of three participants and a maximum of ten have been recommended for this type of inquiry [15, 16]. Individuals were eligible to participate if they were male, between the ages of 18 and 50, living in Canada with an SCI of any level or classification and were able to communicate in English. Due to the novel, and therefore exploratory nature of this research, maximum variation was applied when establishing the inclusion criteria. Despite utilizing a convenience sampling approach, the purposefully broad inclusion criteria enabled a sample of participants that varied in terms of injury and demographic characteristics. This provided a broad view of the issues that exist regarding sexuality in this population. Patterns emerging from varied conditions are valuable in that they capture the core experiences of a phenomenon across contexts and identify factors of particular interest [14]. Recruitment information was posted in relevant SCI groups on social media platforms, and any man who saw the post and was interested in the study was instructed to contact the researcher for more information. The first six men to respond were screened for eligibility, and upon determination that they met inclusion criteria, they were invited to participate. All of the men who inquired about the study and who were eligible to participate agreed to be interviewed.

Rich and detailed descriptions were obtained by means of one-to-one interviews conducted with individuals who had first-hand lived experience with the phenomenon [17]. Participants selected a pseudonym by which they would be referred to throughout the investigation, and each participant completed one in-depth confidential telephone interview (68–101 min; mean time 81 min). Interviews followed a standardized, open-ended approach combined with interview guide approach (see Supplementary Appendix A for interview guide). The same key questions were asked in each interview ensuring conformity in the

Table 2 Sexuality and relationship characteristics.

Participant	Sexual orientation	Relationship		Sexual activity	
		Pre injury	Post injury	Pre injury	Post injury
"Joe"	Heterosexual	In a relationship	In a relationship (different partner than at injury)	No	Yes
"Elliott"	Heterosexual	In a relationship	Married (different partner than at injury)	Yes	Yes
"Will"	Heterosexual	Engaged	Married (same partner as at injury)	Yes	Yes
"Steve"	Heterosexual	In a relationship	Married (different partner than at injury)	Yes	Yes
"Paul"	Heterosexual	Married	Divorced	Yes	Yes
"Peter"	Heterosexual	Married	Married (same partner as at injury)	Yes	No

issues that were discussed with each participant while also allowing for exploration into new and relevant topics that were not anticipated, but which surfaced through discussion [14]. Interview questions were developed based on the previous literature and covered the six question types that have been suggested by Patton [13]: demographic, experience/behavior, knowledge, sensory, feeling/emotion, and opinion/value [14]. Probing questions were used to further investigate certain topic areas. Interviews were audio recorded using a Sony ICD-PX370 digital voice recorder and were transcribed verbatim. Field notes were documented during each interview. Data were analyzed throughout data collection using Giorgi's method [13] and informed subsequent interviews [18]. After all interview transcripts were analyzed individually, a cross-case analysis was performed and interviews were analyzed together to shed light on the phenomenon across various contexts and relationships. Themes between transcripts were identified using Giorgi's method [13] and were supported by direct quotations from participants' transcripts. Data were analyzed independently by two researchers and discussed until consensus regarding prominent themes was reached. A reflective journal was kept throughout the research process to make note of personal thoughts and opinions, to enhance transparency and maintain a record of research decisions generating an audit trail [19, 20].

A researcher's experience, beliefs, and worldviews will ultimately influence the way a study is conducted and presented [17]. The primary researcher who conducted the interviews, performed data analysis, and structured this manuscript is an able-bodied female with more than 10 years of SCI research experience. She has performed numerous qualitative studies, but operates from a post-positivist perspective and applies a quantitative lens to qualitative work [17]. A descriptive phenomenological approach was employed to describe the experience of others with lived experience regarding the phenomenon, and personal interpretation by the researcher was avoided [21]. To ensure the results presented stayed close to the data, direct quotations from participant transcripts were used to support statements made by the author.

Results

Participants

Six men between the ages of 24 and 49 who were living in Canada with complete or incomplete SCI (C4-T12) participated in this study. Participants' time since injury ranged from 7 months to 29 years (mean ~14 years). All of the men identified as being heterosexual.

Unmet need for sexual health information

All of the participants in this study said that the number of resources available and/or provided to them during rehabilitation was inadequate, and that the content of available resources was also inadequate. Generally, the participants explained that sexuality was briefly touched on in rehabilitation, but that it was not a priority, stating there was no real emphasis on the topic and that discussions about sex were *"in passing"* (Joe). They described a lack of time to discuss sexuality with their healthcare providers, as well as a greater focus on other areas of healthcare in rehabilitation programs. *"I think when you're in a rehabilitation setting, they tend to have a lot of focus on like the importance of physiotherapy, the importance of occupational therapy and why you do that. They try to enlighten you on your bladder issues after your spinal cord injury, your bowel issues, the importance of your skin integrity, pressure sores, and they cover a lot of other really important things. But for some reason a lot of them have these really long check lists, but they always leave off the sexual health aspect after spinal cord injury"* (Elliott).

Participants explained that because everyone experiences sexuality differently, it could be difficult to provide relevant information which may contribute to the lack of attention to sexuality in rehabilitation programs. In addition, participants recognized the sensitive nature of the topic and stated sex was not something people wanted to talk about. As a result, it was a difficult conversation for the men to start and they tended to rely on their healthcare providers to initiate the discussion. Unfortunately, this conversation did not always transpire. Joe said: *"[in rehabilitation] sex is just briefly mentioned. Like they ask if you have any questions and then it's done, you never talk about it anymore. There's no actual emphasis on sex and sexual function. It was very much in passing. You could kind of tell they didn't really want to talk about it or that they were just checking it off a list. Just like, 'okay I mentioned sexuality, let's move on to the next thing.' It was very brief. I think because their focus is more on the physical rehabilitation and they are trying to get people moved through there."*

In some situations where information was provided, the participants said that resources did more harm than good by making sex after SCI seem unappealing. One example of this was a VHS tape that portrayed a couple pausing mid-sexual act to allow the man with SCI to empty his bladder with the help of his partner before continuing. Elliott relayed his experience: *"They gave me a really strange VHS tape and it was bizarre (laughs) and probably did more harm than good. It was a tape, specifically about sex after spinal cord injury. And it was from the 80 s. And it was ridiculous. Like it had a bunch of different couples engaging in a variety of different sexual acts*.

Obviously, it exposed me to the reality of it, but at the same time I was like, 'I don't like this and I don't like [it] if that's what the rest of my life is going to look like with spinal cord injury and sexuality." Information provided in rehabilitation and resources accessed on their own from the internet were occasionally unreliable and inaccurate compared to what they actually experienced.

Joe shared: *"Google provided me with some information, but not all that information is correct."* The reported absence of resources was not a result of the men's disinterest in sexuality or sexual education post injury. *"It was a conversation I was thinking about and the conversation that I wanted to have, but they didn't really answer a lot of the questions that I was looking for. So okay, yes you can have sex, but that's where it ended"* (Elliott).

Healthcare provider's knowledge and comfort discussing sexuality

Participants revealed that their healthcare providers were knowledgeable about medications that could assist with sexual activities post injury, including possible complications and interactions, and said that their healthcare providers were somewhat knowledgeable on the physiology and lacked a crucial component for understanding the topic as they did not have any personal knowledge of what it means to experience sexuality after SCI. *"It's hard to say if doctors are knowledgeable about sex after spinal cord injury because not a ton of those conversations have ever taken place. Umm, yes, I mean they're knowledgeable about sexuality in general, but in how it's going to work as a function of life after the injury, meh"* said Paul. As a result, several participants felt they knew more about the topic than their healthcare providers: *"I know from a personal perspective, I probably know more about this [sex after SCI] through all the research that I've done than my spinal cord injury doctor does. So, like he knows a certain amount of things, but I don't think he knows more than I do"* Elliott explained.

Participants said that the information they received from healthcare providers about sexuality was too clinical and too technical. According to the men, healthcare providers failed to address aspects of sexuality beyond the traditional assumption of sex as a physical penetrative act, and focused solely on physical components of sexuality that may be more relevant to individuals who are able-bodied. Participants wished to be educated on new ways to approach sexuality that were "*outside the box*" and that may be better suited to those with SCI. Elliott said: *"It's just like, 'we're not going to help you think outside the box and realize you can use other devices, or you don't just have to get to penetration.'"*

In addition, participants explained that healthcare providers were often uncomfortable discussing sexuality, though this was an assumption for some based on the premise that no conversations about sex had ever taken place. Lastly, participants said that their healthcare providers did not understand the importance of talking about, and learning about, sexuality after SCI. "*…I think a lot of them [healthcare providers] don't really understand the importance of it [sex], and maybe they're not comfortable bringing it up"* explained Elliott.

Importance of receiving sexual health information

Participants clarified that it was important to include the topic of sexual health in rehabilitation programs and to achieve satisfaction in their sexual lives as sexuality was linked to their physical health, mental health, and to their overall well-being. They said that by improving their sexual experiences and sexual satisfaction post injury, other health issues, both mental and physical, would also improve which would lead to improvements in their overall QOL. *"It's [sex] not only linked to your physical health. Like this can have a direct impact on your psychological health and your mental health and it could be triggering a lot of other things [physical and mental health issues]. My thoughts about myself, and just life in general is not always the greatest, but they probably would be if my sexuality was a little bit more positive"* (Elliott).

Participants revealed that sexuality was not prioritized in rehabilitation; however, receiving information about sexuality and having a fulfilling sexual life post injury were identified as being important. For some, being adequately informed about sexuality-related topics could have resulted in different outcomes for their lives. One participant disclosed that he "wasted" time during what should have been his peak sexual activity years due to a lack of sexual education and believing that he could not have sex as a result of his SCI. This participant believed his life may have been different, and that he could be in a different place than he is now if someone had told him that participating in sexual activities and experiencing a satisfying sexual life were still possible post injury. *"I wasted 6–7 years of perfect university time and like experimenting which is what a lot of people do in university. But I skipped over 4 years of my undergrad thinking that a lot of that stuff was not possible. So, I think if somebody told me earlier on that I could still have sex and brought all of this to my attention, I would probably be in a very different position today than I am"* (Elliott).

Recommendations for sexual health information

Participants made recommendations for the most appropriate and effective delivery of sexual health education information post injury. Participants said it could be overwhelming to search for this information on their own and

suggested that it would be most helpful if there was one designated place they could go to find all relevant information, whether that be a designated sex therapist or a "sexpert," an online email address they could send their questions to and receive accurate responses, or an information hub containing links to all of the existing sexual health resources. "*It'd be cool to see them have someone there that's actually trained in sexuality*.

Someone with actual resources. We need a hub of information" said Joe.

Participants were somewhat open to receiving information from a variety of healthcare providers; however, some did convey that while their doctors may be helpful for explaining the physical aspects of sexuality, they would not be the best person to have this conversation with.

Participants said it was difficult to discuss sexuality with their doctors with whom they had existing relationships for fear of being judged. They said that their doctors held a position of power which made it challenging to be vulnerable with this very personal issue, and said that this exchange seemed too formal. Generally, participants preferred to receive this information from a peer, someone of a similar age and injury who could relate to their lived personal feelings and experiences. *"The biggest thing is for the person who's giving you information to say 'oh yeah, the first year of my injury I had these feelings, and often people feel this,' rather than saying, you know, 'there is this medication and this medication' with like a much more kind of textbook-type description. Like more of a personal kind of experience is better"* Joe shared.

Participants identified open communication in a no judgment zone as being important when discussing sex, and said that sex should be incorporated into rehabilitation programs by covering the topic the same way they cover other health issues such as bladder management or skin integrity. Elliott said: *"I think a really easy way to integrate it is to have it as an option. And then okay, you cover bladder one week or bring that up one week, the next week you cover sexuality*.

Because it is really not that different when you think about it, since it's all part of your health care." Having someone reach out early on after injury and open the door for conversations about sex was identified as being important, and a small gesture that could make a big difference would be to just *'bring it up'* and get the conversation about sex going. Joe suggested: *"I think there should be a person that would reach out early on, like a sex specialist*."

Participants also discussed the optimal timing to receive this information. Majority wished to receive information about sexuality immediately after injury, and then continue to receive it when they are back in the community and ready to use it. Peter shared the following: *"I would probably want to know about it as soon as possible. I would like awareness of information*.

Whether you actually execute it or not is different, but I would like to know the facts, all that, ahead of time. And then I can learn from it and be better educated when that time comes." Will had a similar perspective: *"Do it sooner rather than later because that's a problem that we had*.

There were no resources that we were given on how to handle this stuff [sexuality]. If I could make one change in how that's all done, is make sure that that is a topic that's covered as early as possible." Conversely, some men wanted to wait at least a year before receiving this information, explaining that for the first year they had other priorities and/or did not feel like a sexual person. Steve said: *"Oh I would at least give it a year because you're so busy trying to You're trying to do rehab, that sort of stuff."* Considering these two perspectives, information should be made available and offered to men soon after injury which may provide answers to the questions they have early on about sexuality and also inform them that sex is still an option.

Knowing this information is available, the men can choose to access it when they are ready to do so.

Discussion

This study contributed to further understanding the experience of sexuality for men after SCI and revealed that healthcare providers, rehabilitation programs, and available resources are, in general, not meeting the needs of men with SCI. The current literature has reported difficulties integrating the topic of sexual health into rehabilitation programs for those with disabilities [5]. While many healthcare providers do consider sexuality an important issue to approach during rehabilitation, a study of 244 healthcare providers found that only 12% felt sufficiently trained to address the topic [22]. Healthcare providers revealed that sexual health was rarely incorporated in their training curriculum and felt that it was not their professional responsibility to handle [22]. This may account for comments made by the men in the current investigation regarding the availability of sexual health resources and the knowledge and comfort level of their healthcare providers to cover the topic.

Men continue to have concerns about sexuality years after their SCI [23] and agree that continued access to sexual supports after leaving rehabilitation is important, yet there is little consensus regarding the delivery of this information [24]. Healthcare providers working in sexual rehabilitation have identified the need for a standardized and multidisciplinary approach which incorporates expertise from various disciplines to effectively address the complexity of sexual health [5, 25]. Researchers have launched a project to improve standards of SCI rehabilitation in

Canada by 2020, including sexual health. The project aims to encourage a liberal environment regarding sexuality after SCI and to pinpoint sexual health needs through identification, development, and implementation of key indicators related to sexual health after SCI [11]. Initiatives such as these are vital for better meeting the needs of this population regarding their sexual health.

The top preference of the participants in this study for receiving information about sexual health was an informal, nontechnical, nonclinical approach from one designated "sexpert." That being said, open communication in an uncritical environment with someone who is approachable and receptive was important for improving the quality of the interaction between the patient and the healthcare provider. In a study which looked at improving sexual rehabilitation services from the perspective of the patient, McAlonan found that interpersonal skills and character traits of the healthcare provider including an open and friendly personality, and comfort and confidence to both talk and listen during discussions about sexuality were more important than who provided the information and what their role as a healthcare provider was [26].

Participants conveyed that sexual health information would be most beneficial if it took into account the changed body after SCI. They suggested that resources should help them "*think outside the box*" and suggest new ways to explore and experience sexuality. Resources should consider ways of experiencing intimate connection beyond the traditional view of sexuality which has been focused on erection, penetration and ejaculation [8]. Conventional sexual health information should be provided, but it is important that researchers, clinicians, and healthcare providers are open to expanding their views of sex and sexuality when working with this population by considering and discussing alternate ways in which individuals living with SCI may be able to explore and experience sexuality. Finding a balance between open conversation and respecting the comfort level of both the patient and healthcare provider should be explored. Healthcare providers discussing sexual activities post injury should be aware of their own biases and should be prepared to suspend any judgments to facilitate safe and productive discussions about sex [15].

It is important that researchers and clinicians consider the needs of the individuals they aim to assist by involving them in the development and evaluation of programs and treatments, maximizing the potential for benefits to be experienced. Future work should ensure that from the perspective of the patient, sexual health programs are being developed and delivered in an effective and suitable manner.

Strengths and limitations

This qualitative approach allowed the men's voices regarding their own sexuality to emerge. The sample reflected a spectrum of heterosexual men's experiences regarding their sexuality across various ages, time points since injury, injury levels, and injury classifications.

The average time since injury for these participants was ~14 years. It is possible that rehabilitation practices have been updated or improved since some of these men were in rehabilitation programs, though information provided by the most recently injured participant (7 months post injury) was consistent with the others. All of the participants in this study were male and identified as heterosexual. The results from this study may not elucidate the opinions of individuals outside these parameters. The goal of phenomenological work is to uncover the personal lived experiences of individuals who have first-hand knowledge of the topic under investigation and is not meant to be representative of a population [14]. While the small sample size was appropriate for this type of deep and exploratory study, additional research using a larger number of participants may be beneficial for application to a wider population. Data reported here are a subset of information obtained from the interview guide that are relevant to sexual education and sexual rehabilitation post injury. Themes identified from the transcripts in their entirety are intertwined, and the evolving meaning of social constructs related to sexuality for men after SCI should be considered when developing sexual rehabilitation frameworks. Data derived from other sections of the interview guide can be found in [12] and may be reviewed to obtain a deeper understanding of the basis for recommendations made in this paper.

Conclusions

Normalization of the topic of sexuality after SCI is important in facilitating conversations about sex for both patients and healthcare providers [27], and sexual health should be a standard component of rehabilitation that is offered to all patients, not just those who are assertive enough to ask for it [5]. Healthcare providers should be aware of the resources available in their communities [23], and sexual health should be fully integrated into rehabilitation programs and primary care facilities for individuals living with SCI [24]. Participants felt they should have access to a healthcare provider trained in sexuality who would have the skills and resources to address their concerns. Participants also noted that a good first step for moving forward with sexual education post injury would be for healthcare providers to "*just bring up*" the topic and initiate a conversation about sex.

Information from this study may help to inform the development and delivery of effective sexual education for men after SCI and guide future rehabilitation initiatives to improve QOL and overall life satisfaction for these individuals.

Data availability

The datasets generated and analyzed during the current study are not publicly available due to the possibility of identifying information occurring in the in-depth qualitative data, but are available from the corresponding author on reasonable request.

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Author contributions JDK was responsible for developing the protocol, collecting and analyzing data, interpreting results and writing the report. JDK has had full access to the data in the study and has final responsibility for the decision to submit for publication. CMKL contributed to development of the protocol, interpretation of results and provided feedback on the report. DSD contributed to protocol development and provided feedback on the report. HT contributed to protocol development and provided feedback on the report. WHG was responsible for development of the protocol, interpretation of results and provided.

Compliance with ethical standards

Ethics statement This file has been reviewed and received ethics clearance from the York University Research Ethics Board (file number 2019–004) and the Brock University Research Ethics Board (file number 18–235). We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

Conflict of interest The authors declare that they have no conflict of interest.

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Appendix V: ***Published Paper - Utilizing the Delphi Method to Assess Issues of Sexuality for Men Living with Spinal Cord Injury***

Sexuality and Disability
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ORIGINAL PAPER

Utilizing the Delphi Method to Assess Issues of Sexuality for Men Living with Spinal Cord Injury

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Abstract
This study investigated the physical and psychological issues of sexuality for men after spinal cord injury and identified areas of top concern. Using the Delphi Method, a panel of expert judges (twenty men with spinal cord injury [SCI], C3-T12, age 26–59) completed a series of three questionnaires in an attempt to reach a consensus on previously identified issues. It was agreed that SCI affects physical and psychosocial aspects of sexuality and that sexual support is limited for exploring sexuality post-SCI. Additionally, insight into the social constructs of masculinity, gender roles, body image and disability and their influence on the sexual experiences of this population is provided. Enhancing patient, healthcare provider and societal awareness of sexuality for men after spinal cord injury should be an immediate area of focus to improve sexual and overall quality of life for this population.

Keywords Canada · Spinal cord injury · Disability · Delphi method · Male sexuality

Introduction

In a rehabilitation setting, it is estimated that 100% of adults with SCI experience sexual dysfunction and issues with sexual intimacy and sexual relationships [1]. While we are widely exposed to sexuality in society through advertising and social media, exposing and discussing one's personal sexual life remains difficult [2]. Furthermore, while society has shifted towards a greater acceptance of diversity in sexuality this vision may not extend to sexuality and disability where common myths still contribute to the perception of individuals with disabilities as asexual [2]. Though sexual health has been validated as a top

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priority for individuals with SCI, resistance in addressing the topic has led to a disconnect between available resources and need [3].

Spinal cord injury not only affects physical aspects of sexuality, but also social and psychological factors as well [4, 5]. Beyond affecting intimacy, relationships and sexual functioning, the effects of SCI on sexuality may extend to one's identity, self-worth [6] and self-esteem [3], and can lead to social isolation, depression and often contributes to a lower quality of life (QOL) [7]. Learning to adapt to the physical, psychological and psychosocial dimensions of sexuality after SCI is therefore important to living a fulfilling sexual life post-injury [3].

In a recent study by Kathnelson and colleagues [5] in-depth interviews were conducted with men living with SCI. The interviews revealed an extensive list of concerns that men with SCI experience with regards to sexuality post-injury. Topics included physical aspects of sexuality, but focused on psychological and emotional concerns influencing the participants' experience of sexuality post-injury. Issues regarding the availability of sexual health information, tools and resources, as well as the delivery of this information were also identified.

The current study aimed to further explore previously identified issues regarding sexuality among men with spinal cord injury [5] using the Delphi Method; and 2) identify areas of top concern regarding sexuality for men with SCI with a focus on psychosocial factors.

Materials and Methods

The Delphi Method is a consensus tool which systematically and interactively leverages and documents the opinions of an expert panel of judges to reach an agreement on relevant topics [8]. This is accomplished through a series of questionnaires with controlled feedback [9] and is appropriate for use in areas of uncertainty or where knowledge is incomplete [9, 10], including, as with the current study, male sexuality after SCI. The anonymity of the Delphi Method facilitates information exchange on personal and sensitive topics while avoiding the negative dynamics associated with group discussion including status, overbearing personalities and pressures to conform to group ideals [11].

Participants and Recruitment

When utilizing the Delphi method, adherence to a specific set of inclusion criteria is important when selecting the panel of experts. Additionally, a panelist must possess knowledge of, and have practical experience with the topic; a panelist must have the ability, willingness and available time required to participate in the Delphi surveys; and a panelist must possess effective communication skills [9].

Earlier research has confirmed that an effective panel size for use with the Delphi Method is generally comprised of less than 50 individuals [12], and that most studies using this technique engage a panel of 15–20 individuals [13]. Based on these criteria, a panel of 20 experts was recruited. Men with varying levels and classifications of SCI who were over the age of 18, living in Canada and were able to communicate in English were recruited to form our expert panel. Panel members were recruited by means of recruitment posters in the Power Cord Rehabilitation Centre at Brock University, via posts on relevant social media platforms, by distribution of study information to men with SCI through Spinal Cord Injury Ontario and by word of mouth.

Participants provided online consent prior to participating in the study. The first page of the online survey contained a display logic that took the participant to question one of the survey if he chose the response providing his consent to participate. In the event that a participant selected the response that did not provide his consent to participate, he was taken to a screen thanking him for his time before being prompted to exit the survey. This process was repeated at the beginning of the second and third rounds of the survey to ensure ongoing consent. All participants provided consent at all time points. Upon completion of the surveys, participants received a $10 gift card as a thank you for their time. Ethics approval was obtained from the York University Research Ethics Board and from the Brock University Research Board.

Data Collection

An iterative process involving three rounds of questionnaires was employed to reach a consensus on relevant topics [14]. Most Delphi studies use two or three rounds as an increased number of rounds will lead to participant fatigue and ultimately, attrition [11, 15]. In round one, panel members received a structured questionnaire based on the items derived from interviews in Kathenlson et al. [5] (refer to Online Resource 1). Panelists were asked to review the items and indicate their level of agreement on a seven-point Likert Scale that ranged from strongly agree to strongly disagree. Panelists were also asked to rate and rank several items in order of importance. Additionally, three open-ended questions were included to provide the current panelists with opportunities to add their opinions regarding relevant topics that might not have been identified in the earlier research, to clarify or expand on responses from closed-answer questions and to explain any potential issues with the questions. In round two, panel members received a modified questionnaire that had been based on feedback from the previous round, as well as information on the items and their ratings from round one. Information about the position of their scores in relation to the scores of others from round one was provided anonymously and was presented throughout the survey with each question. Panel members were given the opportunity to modify their scores to facilitate movement towards reaching a consensus [9]. In this round, participants were given four opportunities to provide responses to open-ended questions. In the third and final round, the panelists received a list of the remaining items that had not reached a consensus and their ratings as well as a modified questionnaire based on open-ended responses from the previous round. This was the final opportunity for panel members to revise their judgements. If a panel member chose not to change his score and remain outside the group majority, he was given the opportunity to specify his reason(s) for remaining outside the consensus. After three rounds of consultation by our expert panel, the agreed upon items reflected the final list of relevant issues and non-issues regarding sexuality for men after SCI. Surveys were hosted online on Qualtrics^{XM}, an online platform used to obtain feedback from participants via automated and integrated workflows.

Data Analysis

Consensus was defined as $\geq 70\%$ of responses in either the positive end (strongly agree, agree or somewhat agree) or the negative end (strongly disagree, disagree or somewhat disagree) [16–18]. Data were analyzed using measures of central tendency (mean and mode) to demonstrate total group ratings. These tests revealed the level of consensus that was achieved and determined whether convergence, or a move towards central tendency,

and thereby an increase in the strength of the agreement was accomplished throughout the three rounds [19–21]. Qualitative data from open-ended questions were analyzed using conventional content analysis [9]. Data were read repeatedly by the primary investigator and central thoughts and concepts were noted. Codes representing these key ideas were derived from the data and were organized into categories that described the perspectives of the participants [22].

Results

Participants

Twenty men between the ages of 26 and 59 (mean age 43.6 years; 10% age 25–29, 10% age 30–34, 5% age 35–39, 30% age 40–44, 15% age 45–49, 20% age 50–54, 10% age 55–60) living in Canada with complete (55%) or incomplete (45%) SCI (C3 - T12) were recruited to form the expert panel. The average time since injury for the panelists was 16.75 years, and ranged from < 1 year to 33 years. All of the men identified as heterosexual. Eighteen of the men had participated in sexual activities and had had sexual intercourse prior to their respective injuries. Seventeen men had participated in sexual activities post-injury and sixteen had had sexual intercourse post-injury. Relationship statuses at the time of the study were single (20%), separated (5%), divorced (5%), in a relationship (20%), common law (20%) and married (30%). Table 1 outlines demographic and injury characteristics, and Table 2 outlines sexuality and relationship characteristics.

Table 1 Demographic and injury characteristics

Age group	Injury level/classification	Time post-injury
40–44 years	C7 incomplete	21–25 years
35–39 years	T6 complete	31–35 years
45–49 years	T12 incomplete	16–20 years
25–29 years	T4 complete	6–10 years
40–44 years	T12 incomplete	21–25 years
25–29 years	C7 incomplete	6–10 years
40–44 years	C5 complete	11–15 years
45–49 years	T4-T5 complete	< 1 year
50–54 years	C3 incomplete	11–15 years
40–44 years	T6 complete	21–25 years
55–60 years	T3 complete	31–35 years
50–54 years	T11-T12 incomplete	1–5 years
50–54 years	C7 incomplete	31–35 years
40–44 years	T12 complete	1–5 years
55–60 years	T10 complete	26–30 years
45–49 years	C3-C4 incomplete	16–20 years
40–44 years	C5 complete	1–5 years
30–34 years	C6-C7 incomplete	11–15 years
30–34 years	T2 complete	1–5 years
50–54 years	T7-T8 complete	26–30 years

Table 2 Sexuality and Relationship Characteristics

Sexual orientation	Relationship status		Sexual activity		Sexual intercourse	
	Pre-injury	Post-injury	Pre-injury	Post-injury	Pre-injury	Post-injury
Heterosexual	Single	Common-law	Yes	Yes	Yes	Yes
Heterosexual	Single	Common-law	No	Yes	No	Yes
Heterosexual	Married	In a relationship	Yes	Yes	Yes	Yes
Heterosexual	Single	Single	Yes	Yes	Yes	Yes
Heterosexual	Single	In a relationship	Yes	Yes	Yes	Yes
Heterosexual	In a relationship	In a relationship	Yes	Yes	Yes	Yes
Heterosexual	In a relationship	Single	Yes	Yes	Yes	Yes
Heterosexual	Unknown	Married	Yes	No	Yes	No
Heterosexual	Unknown	Divorced	Yes	Yes	Yes	Yes
Heterosexual	Single	Common-law	Yes	Yes	Yes	Yes
Heterosexual	Married	Married	Yes	Yes	Yes	Yes
Heterosexual	Married	Married	Yes	No	Yes	No
Heterosexual	In a relationship	Married	Yes	Yes	Yes	Yes
Heterosexual	Married	Married	Yes	Yes	Yes	Yes
Heterosexual	Single	In a relationship	Yes	Yes	Yes	Yes
Heterosexual	Single	Separated	Yes	Yes	Yes	Yes
Heterosexual	Married	Married	Yes	No	Yes	No
Heterosexual	In a relationship	Common-law	No	Yes	No	Yes
Heterosexual	Single	Single	Yes	No	Yes	No
Heterosexual	In a relationship	Single	Yes	Yes	Yes	Yes

Round One

Twenty surveys were distributed in the first round with a 100% response rate. In this round, 28 of 60 items reached a consensus (46.7%). Of those 28 items, 15 (53.6%) reached a level of moderate agreement with ≥ 70% of responses in either the positive end (strongly agree, agree or somewhat agree) or the negative end (strongly disagree, disagree or somewhat disagree). Thirteen items (46.4%) reached a level of strong agreement with ≥ 70% of responses in either the high positive end (strongly agree or agree) or high negative end (strongly disagree or disagree) [16–18]. Table 3 lists the items that reached a consensus in round one.

Round Two

After distribution, participants were given one week to complete the second survey. Two follow-up e-mail reminders were sent to non-responders (three days after the initial survey distribution and a final reminder the day before the survey would close). Seventeen of 20 surveys were returned (85% response rate).

The 32 items that did not reach a consensus in round one were restructured based on feedback provided by participants (either altering the wording of the question or adding additional response choices), and were examined again in round two. Based on feedback

Table 3 Items reaching a consensus in round one

Question	Level of agreement	Percent agreement
I believe that sex is both a physical and a psychological/emotional experience	Strong agreement	95% high positive 100% positive end
I believe that sexuality is about more than just sex	Strong agreement	95% high positive 95% positive end
I think that sex involves more than just penetration	Strong agreement	95% high positive 100% positive end
Emotional closeness with my partner during sex has become more important since my SCI	Moderate agreement	45% high positive 70% positive end
I think the sexual experience is more enjoyable when there is an emotional/psychological connection with my partner rather than just a physical connection	Strong agreement	95% high positive
Finding new ways to experience sexual satisfaction has become more important since my SCI	Moderate agreement	80% positive end
Open and honest communication with my partner about sex has become more important since my SCI	Strong agreement	70% high positive 80% positive end
I focus more on my partner's sexual satisfaction since my SCI	Strong agreement	70% high positive 75% positive end
I get sexual satisfaction through my partner's sexual satisfaction	Strong agreement	90% high positive
The way I view my own masculinity has changed since my SCI	Moderate agreement	75% positive end
People only see my SCI when they first look at me	Moderate agreement	75% positive end
Because of my SCI, I am concerned for my physical safety when meeting new people	Strong disagreement	80% high negative 85% negative end
Changes in my body functions since my SCI have negatively affected my sexual life	Strong agreement	75% high positive 85% positive end
Changes in my sexual function since my SCI have added stress to my relationships	Moderate agreement	70% positive end
Decreased spontaneity in my sexual life due to SCI has had a negative effect on my sexual life	Moderate agreement	85% positive end
Positively adjusting to sexuality after SCI contributes to my personal growth	Moderate agreement	85% positive end
The longer I live with SCI, the more accepting I am of my injury	Moderate agreement	80% positive end

Table 3 (continued)

Question	Level of agreement	Percent agreement
I wanted to receive education about sex after SCI	Strong agreement	70% high positive 80% positive end
I think it is important to receive education about sex after SCI	Strong agreement	80% high positive 90% positive end
I would find it helpful to receive information about the physical aspects of sexuality after SCI	Moderate agreement	75% positive end
I would find it helpful to receive information/counselling about the psychological/emotional aspects of sexuality after SCI	Moderate agreement	70% positive end
Most of my knowledge about sex after SCI came from my health care providers	Strong disagreement	80% high negative 85% negative end
Most of my knowledge about sex after SCI came from my own research	Strong agreement	75% high positive 85% positive end
I think the information provided by health care professionals regarding sex after SCI is missing the personal experience that comes with actually living with a SCI	Moderate agreement	80% positive end
Increased sexual education after SCI could lead to increased sexual satisfaction	Moderate agreement	75% positive end
I am knowledgeable about alternate ways to achieve sexual satisfaction after SCI	Moderate agreement	70% positive end
I am affected by the misconceptions that society has about men who live with a SCI	Moderate agreement	75% positive end
Educating society about what it actually means to live with SCI could improve the dating experience	Moderate agreement	80% positive end

provided in round one, five additional items were developed and incorporated in round two. A total of 37 items were included in round two, and 13 reached a consensus (35.1%). Twelve items (92.3%) reached a level of moderate agreement with ≥ 70% of responses in either the positive or negative end, and 1 item (7.7%) reached a level of strong agreement with ≥ 70% of responses in the high positive end. Table 4 lists the items that reached a consensus in round two.

Round Three

In round three, seventeen surveys were distributed and participants were again given one week to complete them. Follow-up reminders were sent to non-responders at the same intervals described in round two. Fifteen surveys were returned in the third and final round (response rate of 88%).

The 24 items that did not reach a consensus in round two were restructured based on feedback provided by participants and were asked again in round three. Of these 24 items, nine reached a consensus (37.5%). All nine items that reached a consensus were at a moderate level of agreement with ≥ 70% of responses in either the positive end or the negative end. No items in this round reached a level of strong agreement. Table 5 lists the items that reached a consensus in round three.

After three rounds of surveys, a total of 15 out of 65 items (23.1%) did not achieve the minimum criteria to be considered a consensus. Table 6 lists the items that did not reach a consensus.

Discussion

Sexuality

Sexuality may be defined and experienced in many ways [23]. The men in this study strongly agreed that sex was both a physical and psychological experience that was more enjoyable when there was an emotional connection with their partner rather than just a physical connection. Previous research has also communicated this and has found that men with SCI experienced little meaning or gratification in sexual activities unless they were in a close relationship in which they cared for their partner [23, 24].

The men in this study agreed that sex was about more than penetration and agreed that sex had less to do with penetration since their SCI. Consistent with earlier interviews [5], other types of physical connection had become more important than the act of penetration. Physical closeness includes more than just genital touching [23], and sexual gratification may be experienced in many ways including touching, cuddling, kissing, laying together and oral sex, not just genital intercourse [5, 25]. One participant stated, "*I spend less time having penetrative sex now and more time with other types such as oral.*" Furthermore, closeness may not mean only in a physical sense, but in an emotional sense as well. In a study by Leibowitz and Stanton [26], participants with SCI conceptualized sexuality in a way that stretched beyond purely physical sexual acts. The focus was less physical and included "*mental, spiritual, and emotional aspects of sexuality*" [26]. Though some participants had reported sexuality as a predominantly physical experience prior to injury, none of the participants described sexuality in a purely physical, genital experience after injury.

Table 4 Items reaching a consensus in round two

Question	Level of agreement	Percent agreement
Sex has less to do with penetration since my SCI	Moderate agreement	43% high positive 79% positive end
I think that men with SCI are viewed as less masculine than men who are able-bodied	Moderate agreement	63% high positive 75% positive end
Dating is not worth the effort because I spend a lot of time explaining my injury and then the person is not interested anyway	Moderate agreement	62% high positive 70% positive end
If I was single, people may not want to date me because they don't want to end up being my caregiver	Moderate agreement	25% high positive 70% positive end
I am afraid of, or have been afraid of letting my partner down sexually	Moderate agreement	50% high positive 81% positive end
Changes in the way my body looks after SCI have at some point had a negative effect on my sexuality	Moderate agreement	44% high positive 75% positive end
I feel like something is missing from my life when I think about my sexual experiences now compared to before my SCI	Strong agreement	80% high positive 93% positive end
Sexual education was not a priority of my health care providers when I was in rehabilitation	Moderate agreement	63% high positive 88% positive end
I believe the information provided by health care professionals regarding sex after SCI is too clinical	Moderate agreement	39% high positive 77% positive end
I had my own misconceptions about living with a SCI that I had to overcome after my injury	Moderate agreement	56% high positive 86% positive end
At some point since my SCI, I have questioned what would make me attractive to a partner	Moderate agreement	59% high positive 88% positive end
At some point since my injury I have compared my body to men who do not have a SCI	Moderate agreement	65% high positive 82% positive end
Decreased self-esteem negatively affects my sexuality	Moderate agreement	24% high positive 76% positive end

Table 5 Items reaching a consensus in round three

Question	Level of agreement	Percent agreement
Physical closeness (touching, cuddling, laying together) to my sexual partner has become more important than the act of penetration since my SCI	Moderate agreement	50% high positive 71% positive end
I avoid approaching new potential partners because I am afraid of being rejected	Moderate agreement	50% high positive 70% positive end
I have questioned my ability to attract a partner since my SCI	Moderate agreement	58% high positive 75% positive end
Changes to my level of independence after SCI have at some point negatively affected my self-esteem	Moderate agreement	60% high positive 73% positive end
Changes to my level of confidence after SCI have at some point, or my in the future negatively affect my self-esteem	Moderate agreement	47% high positive 75% positive end
My partner is afraid of hurting me during sex	Moderate disagreement	70% negative end
Having to monitor my body, or thinking about having to monitor my body during sexual activities may take away from the sexual experience	Moderate agreement	33% high positive 73% positive end
I try not to think about sexuality by refocusing my attention on other things	Moderate disagreement	53% high negative 73% negative end
My health care providers are knowledgeable about sex after SCI	Moderate disagreement	62% high negative 77% negative end

Table 6 Items that did not Reach a Consensus

Question	Result
If I put more focus on the emotional/psychological connection with my partner, the sexual experience can be more satisfying than it was prior to my SCI	57% positive end
I am afraid that I will have to settle in terms of the partner I end up with	50% positive end
I have a fear of failure when in a sexual situation or when thinking about being in a sexual situation	47% positive end
Changes in my sexual function since my SCI have caused relationships to end	46% negative end
Due to my SCI, cleanliness of my body has, or may be, a concern during sexual activities	60% negative end
I am anxious about the side effects of medications that would help me have an erection (e.g. Viagra, Cialis etc.)	47% positive end
Increased planning in my daily life due to SCI has had, or may have a negative effect on my sexual life	67% positive end
I am satisfied with the amount of information I received regarding sexuality after SCI	53% negative end
My health care providers are comfortable discussing sex after SCI with me	50% negative end
I am satisfied with the resources that are available regarding sex after SCI	60% negative end
I spend a lot of time educating my partner/potential partners about sex after SCI	46% positive end
It is difficult to have a conversation about how sex works after SCI with partner/potential partner	57% negative end
There are adequate resources available for my partner to access to learn about sex after SCI	64% negative end
I have a lower sexual drive now than I did prior to my injury	60% positive end
At some point since my injury I have compared my sexual performance to men who do not have a SCI	60% positive end

Emotional intimacy was rated as being more important than physical intimacy, and the level of sexual intimacy experienced was enhanced post-SCI.

The men did not reach an agreement on whether focusing on the psychological and emotional connection with their partner could make the sexual experience more satisfying than it was prior to injury. One participant shared, *"reduced sensation negatively affects my sexual satisfaction beyond what any compensatory methods can improve."* Though a consensus was not achieved, the highest number of responses did fall in the positive end, and 57% of men reported that by focusing on psychological and emotional connections, their sexual lives could be more satisfying than they were prior to injury.

The men reported that exploring new ways to experience sexuality was more important post-injury. Previous literature has stated that sexual exploration is important after SCI as men may experience decreased genital sensation and may be unaware of other areas of the body capable of producing pleasurable sensations [25]. Through sexual exploration, new erogenous zones may be identified [24]. The men generally agreed that they were knowledgeable about alternative ways to achieve sexual satisfaction post-injury, and also agreed that open and honest communication about sex with their partners had become more important post-injury.

The men stated that they tended to focus more on their partners' sexual satisfaction now than they did prior to injury, and agreed that they experienced satisfaction through their partners' sexual satisfaction, which was consistent with the preliminary interviews [5]. Previous literature has also found that men with SCI experience satisfaction through

the pleasure their partner experiences upon reaching orgasm. Hohmann [23] describes *"empathetic gratification"* in which an individual with SCI may experience psychological and physical responses associated with build-up and orgasm at the same time the partner reaches orgasm. This phenomenon was referred to as a "*para-orgasm.*" Men with SCI have also reported not being as concerned with their own sexual pleasure [25], and one participant in the current investigation wrote, *"Not being able to orgasm myself is very low on my priority list, but not being able to give in every way is tough mentally to deal with as a man."*

The men agreed that they are, or have been, afraid of letting their partner down sexually since their injury, but did not agree that they have a fear of failure when in a sexual situation. One participant explained, "*confidence overcomes and meds [medications] help.*" Other men shared that being in a *"solid relationship"* also helps.

Though no consensus was reached, many men (60%) reported comparing their sexual performance to men who do not have a SCI. In an additional comment, one man wrote, *"I can't help but compare my sexual functioning to other neuro-typical men my age, and sometimes this makes me feel less virile."* In contrast, one man who did not respond with the group said *"I don't care what other men do. It's like comparing myself to porn, unrealistic and we are whom we are."* Comparing sexual experiences and sexual performance pre and post-injury can have potentially detrimental effects. Perceptions of pre-injury sexual performance are subject to a memory bias and may be skewed as men tend to glorify their previous sexual experiences [25]. The men strongly agreed that something was missing from their lives when they thought about their current sexual experiences compared to those before SCI, and agreed that they try not to think about this by refocusing their attention on other things.

No consensus was reached regarding the topic of sexual drive, however, the highest number of responses (60%) did fall in the positive end suggesting the men had a lower sexual drive post-injury compared to before SCI. Men who did not respond with the group provided the rationale that *"my sex drive is just as high, I enjoy sex," "my sex drive hasn't changed, just my ability,"* and *"the chair [wheelchair] has nothing to do with my sex drive."* In previous literature, psychosexual desire has been reported to remain similar after SCI, and patients with SCI often maintain the same sexual interests they had prior to injury [27, 28]. Using the Sexual Functioning Index, Romeo, Wanlass and Arenas [29] found no difference in sexual drive or sexual fantasies between men with SCI and men who did not have a SCI.

Prior research has found that the majority of individuals strongly feel that their SCI has interfered with their sexual activities [3]. The men in the current investigation agreed that changes in their bodily functions and appearance as a result of SCI had negatively affected their sexual lives, and that changes to their sexual function had added stress to their relationships. However, the highest number of responses (46%) did not agree that changes to their sexual function had caused relationships to end. Conversely, one participant whose response remained against the group shared, "*I've had two relationships end solely because of my injury.*" This comment may be more in line with previous research which has found an initial period after SCI where there is a significantly higher risk of divorce and separation [30, 31] due to difficulties adapting to altered physical function and challenges maintaining the relationship [32].

In general, the men reported that they did not believe that their partners were afraid of hurting them during sex, but having to monitor their body for potential issues during sexual activities was thought to take away from the sexual experience. Also taking away from the sexual experience was decreased spontaneity in their sexual life as a result of the injury. One

participant explained, "*being unable to have intercourse is a hard thing to deal with as a man… Not being able to have a spontaneous erection has been very difficult emotionally.*" Accordingly, these concerns were reported to have a negative impact on the sexual life of these men. While decreased spontaneity in their sexual life was problematic, the men did not agree that increased planning in their daily life due to SCI had a negative effect on their sexual life. Due to physical limitations that made performing personal hygiene activities increasingly difficult it had been previously noted that, cleanliness of the body during sexual activities could be a concern [5]. The men in the current study did not agree that cleanliness of their body was a concern during sexual activities, stating that *"cleanliness is always important, regardless of SCI or not,"* but one participant noted that *"bowel and bladder functions have to be a concern [after SCI]."* The men did not agree that they felt anxious about the side effects of medications that would help them have an erection.

In this study, participants in higher age ranges (50 to 60 years of age) continued to identify sexuality as an important aspect of their lives. This is consistent with Lombardi and colleagues [33] who found that sexuality continued to be important to men over the age of 50 and men who had been injured for over 20 years. This has also been recorded in numerous other sources [34–36].

Societal Views

The men agreed that people see only their SCI when they first look at them, and agreed that they have been affected by the misconceptions that society has about men who live with a SCI. The men also had their own misconceptions about living with a SCI that they had to overcome after injury.

In general, the men agreed that dating was not worth the effort due to the amount of time they spent explaining their injury to a new potential partner only to find out that the person was not interested anyway. The men did not reach a consensus on whether it was difficult to have a conversation about how sex works after SCI with a sexual partner, or potential sexual partner, but many men answered that it was not difficult if you have an understanding partner and if you are an open person by nature. One man wrote, *"sex is sex. If you're not talking to your partner about it, you're not going to enjoy each other or make each other happy in their ways."* Another man shared, *"time needs to be taken to talk about sex and everything that goes along with it post-SCI."* The men did not reach a consensus regarding whether they spent a lot of time educating their partners about sex after SCI and responses were based on personal preference. One man shared, *"I do not spend much time explaining, I try to focus on what I can do, not what I can't."* This is in line with Talbot [27], who wrote, "*it is more important to concern ourselves with what is left than with what has gone."* Participants agreed that people may not want to date a man with SCI because they do not want to become his caregiver. Men also agreed that educating society about what it means to live with a SCI could improve the dating experience. As an additional comment, one man shared, "*the biggest obstacle I face as a man with an SCI is being seen as sexual. This needs to be addressed to society more. We are the same, we want the same things, we are viable sexual partners."*

Self-View

Participants agreed that men with SCI are viewed as less masculine than men who are able-bodied. They also agreed that the way they viewed their own masculinity had changed post-injury.

Physical changes due to SCI are, unsurprisingly, associated with shifts in self-perception [29]. Sexual difficulties not only affect sexuality, they also affect one's identity and self-worth [6]. Consistent with Reel and Davidson [2], the participants in this study agreed that sexuality after SCI comes with emotional risks and risks to self-esteem including rejection, embarrassment, shame, disappointment, failure and negative self-view. A consensus was reached and the men agreed that at some point since their injury, they had compared their body to that of an able-bodied man, questioned their ability to attract a partner, questioned what would make them attractive to a partner, or potential partner, and had avoided approaching a new potential partner post-injury for fear of being rejected. One man commented, "*Prior to being in a committed relationship I was very fearful and anxious about engaging in sexual relationships. I did not believe I was capable of attracting a desirable mate and that my bodily functions would interfere."* Similarly, women with SCI have also questioned whether they could be desired sexually [26].

Dependency after SCI may evoke childlike feelings and affect a man's identity or sense of self [25]. The men in this study reported that changes to their level of independence, as well as changes to their level of confidence had, at some point, both negatively affected their self-esteem. The men agreed that decreased self-esteem had a negative effect on sexuality.

Generally speaking, the men reported that they did not think they would have to settle in terms of the partner they would end up with. One participant explained, *"I would prefer to remain single than to settle for someone I was not really interested in."* In contrast, another participant shared, *"I feel I am unable to attract the same type of partner since my SCI."*

Information and Education

Consistent with Kathnelson and colleagues [37] the men in this study strongly agreed that it was *important* to receive information about sex after SCI, and strongly agreed that they *wanted* to receive information about sex post-injury. The men agreed it would be beneficial to receive information regarding both the physical aspects of sexuality, as well as the psychological and emotional aspects of sexuality. It was also agreed that increased sexual education after SCI could lead to increased sexual satisfaction.

Responses varied with regards to whether the men were satisfied with the amount of information they received regarding sexuality after SCI. More men reported that they were not satisfied than reported being satisfied, and it was noted that in their experience, some clinicians seemed to find sex awkward to discuss. However, one man shared that many of his peers and healthcare providers were open and helpful, and another man commented that he had access to specialized SCI sexual health clinicians that provided excellent education and clinical support. Additional remarks included that it is up to the individual with SCI to ask the right questions and take responsibility for their own sexuality; that they should not rely on others to *"spoon feed"* them the information, and that everyone is different so they need to seek out information on their own.

There was no consensus regarding whether the men were satisfied with the number of resources available for sex after SCI, though a higher number of men (64%) reported being unsatisfied than were satisfied. One participant who was satisfied stated, *"the resources are out there if you choose to search for answers to your questions."* Participants mentioned that peer mentors were a good resource. Healthcare providers should be aware of existing resources and should enlighten their patients on where and how to access them. Also consistent with Kathenlson and colleagues [37], the men agreed

that sexual education was not a priority of their healthcare providers when they were in rehabilitation; they agreed that most of their knowledge on the subject came from their own research, not from their healthcare providers. The men generally agreed that their healthcare providers were not knowledgeable about sex after SCI, but were divided on whether their healthcare providers were comfortable discussing sex after SCI. Some comments included, *"healthcare providers have no actual clue about sexuality with disability"* and *"it never feels like they [healthcare providers] care."* One participant noted that he *"can't tell how comfortable they [healthcare providers] are [discussing sex after SCI]."* Aligning with previous work [37], participants agreed that the information they received from their healthcare providers was too clinical and was missing a sense of personal experience that comes from actually living with a SCI.

Though a consensus was not reached, many of the men (64%) reported that the resources available for their partners to learn about sex after SCI were inadequate. Men who responded against the popular opinion provided the rationale that *"online resources are readily available, if your partner chooses to look for them."*

An identified hurdle for discussions about sexuality in healthcare settings is an uncertainty of whose responsibility it is to bring up the topic [38–40]. Patients may be anxious or embarrassed to bring up this issue with their healthcare providers and may not know with which healthcare provider they should have this discussion [41]. Patients often wait for their healthcare providers to begin discussions about sex, but due to healthcare provider barriers including a lack of knowledge, lack of comfort and lack of clarity, the topic of sexuality may not be raised [37, 42]. A recent study found that 24 out of 25 surveyed nurses felt that they required specific training on starting a conversation about sex with their patients [38]. Integrating and building the topic of sexuality into patient rehabilitation schedules and programs may be a mechanism to ensure the topic is addressed while eliminating the question of who should initiate the conversation [37, 38, 43]. Having a physical space where these discussions can take place privately may also facilitate conversations about sexuality [38].

Acceptance

Corroborating previous work from Kathnelson et al. [37], the men in the current study agreed that they became more accepting of their injury with increased time since injury, and that positively adjusting to sexuality post-injury contributed to their personal growth. As an additional comment, one man shared, "*becoming comfortable with your disability is key to a happy and healthy sex life."* Acceptance by others also facilitated adjustment to sexual life, and life in general post-injury: *"after being in a very committed relationship, feelings of loneliness, anxiety, shame, and frustration have all subsided. There is still frustration about decreased sensation in the sexual organ, as well as pain and spasticity, however, I am better adjusted*." McAlonan [44] also found that time, experience and supportive partners were vital to adjustment, acceptance and a fulfilling sexual life for individuals with SCI. Rehabilitation services should aim to support and enhance men's acceptance of their new life post-injury to improve their sexuality, and overall QOL [45]. Conversations with men living with SCI and who have preserved a positive view of their sexuality may also be beneficial for newly injured men [25].

Rate and Rank

Body image issues that were most often a concern during sexual activities as identified by ≥ 50% of participants included: flaccid penis, loss of muscle tone, larger stomach and always being in a seated position. Participants were less often concerned about atrophied legs, pressure sores, not being able to wear certain clothes and scars from injury or surgery.

The most common fear that prevented men from participating in sexual activities was the fear of bladder incontinence (50%). Other issues identified by the men included bowel incontinence, autonomic dysreflexia, pain, spasticity and getting hurt, though each was identified by less than 50% of participants.

Frustration was the most commonly experienced emotion after SCI, which affected the sexuality of 80% of participants. Other emotions affecting sexuality that were identified by ≥ 50% of participants included depression, loneliness, embarrassment and exhaustion/fatigue. Emotions experienced by less than 50% of participants which affected sexuality included: anger, amazement, pride, anxiety, mourning (sadness) and shame. A study by Romeo, Wanlass and Arenas [29] compared the psychosexual functioning of men with SCI to an able-bodied group of men using the Psychological Symptoms Scale of the Derogatis Sexual Functioning Inventory (DSFI) and found the group with SCI reported significantly higher levels of psychological distress than the men without SCI. Intact sexual desires coupled with altered sexual performance can be a source of frustration, shame and distress due to the negative impact on a man's sense of masculinity [46]. Additionally, unsuccessful sexual endeavors after SCI may lead to anger, frustration and relationship conflict [25]. In this study, positive sexual experiences were said to increase confidence (65%), lead to increased participation in sexual activities (65%) and have a positive effect on overall QOL (60%). Table 7 outlines body issues and sexual experiences.

The most popular response regarding when the men would like to receive information about sexuality was while in rehabilitation (75%), followed by wanting the delivery of information to remain ongoing (65%). Participants in a study by Northcott and Chard [47] who had lived with SCI for many years still felt the need for sexual supports which is consistent with the identified need for ongoing information regarding sexuality reported in this study.

Participants' top choices regarding who they would like to receive this information from were relationship counsellors, and other men with SCI (both 65%). The two bottom choices were nurses (35%) and occupational therapists (25%). None of the men reported that they did not want to receive information about sex after SCI. Consistent with other studies [5, 38], the participants in this study agreed that having a sexologist or sex therapist would be a beneficial addition to their rehabilitation team.

The men preferred to be educated about sexuality through conversation rather than by reading an educational resource. The top choices regarding how the men would like to receive information about sexuality after SCI were via conversation with a healthcare provider (75%), followed by conversation with another man with SCI (70%). The two bottom choices were via pamphlet (40%) and book (30%). Table 8 outlines the preferences for delivery of information.

Table 7 Body issues and sexual experiences

	Percent agreement
Body image issues that I have been concerned about include	
Flaccid penis during sexual activities	80%
Loss of muscle tone	65%
Larger stomach	60%
Always being in a seated position	50%
Atrophied (smaller) legs	35%
Pressure sores	30%
Not being able to wear certain clothes	15%
Scars from injury/surgery	5%
A fear of the following issues has prevented me from participating in sexual activities	
Bladder incontinence	50%
Bowel incontinence	35%
Autonomic dysreflexia (high blood pressure)	20%
Pain	20%
Spasticity	15%
Getting hurt	5%
I have experienced the following emotions since SCI that affect my sexuality	
Frustration	80%
Depression	55%
Loneliness	50%
Embarrassment	50%
Exhaustion/fatigue	50%
Anger	45%
Amazement	35%
Pride	35%
Anxiety	30%
Mourning (sadness)	30%
Shame	25%
Negative sexual experiences after SCI	
Lead to avoidance (decreased participation) in sexual activities	45%
Decrease my confidence	35%
Have a negative effect on my overall quality of life	25%
Positive sexual experiences after SCI	
Increase my confidence	65%
Lead to increased participation in sexual activities	65%
Have a positive effect on my overall quality of life	60%
Help me accept my injury	40%
Give me hope for the future	35%

Strengths, Limitations and Future Directions

This study included a broad range of participant experiences from across Canada. This provided a comprehensive insight into the sexuality of men with SCI of different ages,

Table 8 Information about sex after SCI

	Percent agreement
The best time to receive information about sex after SCI is	
While in rehabilitation	75%
Ongoing	65%
0–6 months after injury	45%
6–12 months after injury	40%
Immediately after injury and again once you are back in the community	30%
Immediately after injury	25%
1–2 years after injury	20%
More than 2 years after injury	20%
I do not want to receive information about sex	15%
I want to receive information about sex after SCI from	
Relationship counsellor	65%
Another man with SCI	65%
Doctor	55%
Physiotherapist	40%
Psychologist	40%
Nurse	35%
Occupational therapist	25%
I do not want to receive information about sex	0%
I would like to receive information about sex after SCI in the following way(s)	
Conversation with healthcare provider	75%
Conversation with another man with SCI	70%
Internet	55%
Video	50%
Group discussion	45%
Pamphlet	40%
Book	30%
I do not want to receive information about sex	5%

injury levels, injury classifications, durations since injury, relationship statuses and from different areas within the country. Through utilization of the Delphi Method, anonymity of participants may have reduced the pressure to conform their responses to those of the group. The feedback participants received throughout the study may have deepened insights into their own sexuality and helped validate and normalize their own concerns about sexuality after SCI by discovering that others shared similar experiences.

Five participants were lost over the three rounds, with 15 of the initial 20 men completing the entire Delphi process. Attrition is a known concern associated with the Delphi Method, and many guidelines recommend using two rounds of surveys to prevent response fatigue and participant burnout [48]. The present investigation tasked participants with completing three rounds to obtain a deeper understanding of survey items, but this may have contributed to participant loss. Moreover, recruitment proved to be a challenge and men who were among the first to complete round one of the survey had additional time elapse before receiving the second survey, which could have also affected participant

retention. Despite the loss of five participants from round one to round three, a final sample size of 15 men after three rounds of the survey remains within recommended guidelines [13].

Studies about sexuality may attract participants who are open and liberal in their views of sexuality as they may be more comfortable participating in studies about sex. Participants in the current investigation were self-selected, and individuals from cultures and ethnic backgrounds that are less liberal towards sexuality and those who practice religions with restrictive views on sexuality (i.e., stringent views on sexual relations outside of marriage, different sexual orientations, masturbation, etc.) may not have volunteered to participate. The results of this study may not capture the views of such individuals.

There is a known link between mood and sexuality, and negative thoughts, feelings and emotions often have an adverse effect on sexual functioning [42]. Emotions experienced by the participants in the investigation, including depression, loneliness, embarrassment and exhaustion/fatigue, as well as the changes to self-view experienced by participants warrants further investigation and should be considered in rehabilitation services [28].

While there has been a focus on the physical aspects of sexuality for men living with SCI [49], sexuality is also comprised of psychological, emotional, sociocultural and interpersonal factors that must be explored [50, 51]. Considering the findings from this study and others [35, 37, 38, 41, 42, 50] there is ample support for the importance of utilizing a biopsychosocial approach in conjunction with a multidisciplinary team to deliver a comprehensive sexual health rehabilitation and education program to individuals living with SCI.

Conclusions

Sexuality is, and consistently has been, established as an area of utmost importance for individuals with SCI, and that continues to be relevant long after injury [3, 4, 36, 43]. However, this is inconsistent with the reported experiences of men with SCI indicating a perception that this issue is of low priority to healthcare providers and that little attention is given to sexual health education for men after SCI, resulting in a disparity in care [3, 4, 43, 52] that has negatively affected QOL for these individuals [43].

Sexual adjustment after SCI is connected to body-image, self-esteem and psychological well-being [29], and sexual capability is important to one's psychosocial rehabilitation post-injury [27]. Society communicates and reinforces harmful myths about sexuality, disability and masculinity, and interventions should be implemented to change negative attitudes and strengthen positive beliefs regarding sexuality for men after SCI. In doing so, societal norms and emotional responses may be amended for men with SCI, their healthcare providers and the community as a whole [53], improving the landscape of sexual adjustment for this population. A comprehensive sexual health program that supports sexual adjustment from both the physical and psychosocial perspectives is necessary for enhancing sexual enjoyment post-injury [25] and should be implemented as the standard of care for sexual health in the future.

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